



**MARKET RESEARCH ON THE
INFORMATION NEEDS OF HCFA
BENEFICIARIES
GENERAL MEDICARE
POPULATION FOCUS GROUPS**

Prepared for:

Health Care Financing Administration
Contract No. 500-95-0057/T.O. #2

Prepared by:

Westat
Barbara H. Forsyth
W. Sherman Edwards

September 18, 1997

| |
|--|
| |
|--|

CONTENTS

| Chapter | | Page |
|----------|--|-----------|
| | EXECUTIVE SUMMARY | iii |
| 1 | INTRODUCTION | 1 |
| 1.1 | Overview of the HCFA Beneficiary Market Research | 1 |
| 1.2 | Overview of the Market Research Project on the Information Needs of HCFA Beneficiaries..... | 2 |
| 1.3 | Overview of Focus Group Report..... | 3 |
| 2 | FOCUS GROUP METHODS AND DESIGN..... | 5 |
| 2.1 | Overview of Focus Group Methods | 5 |
| 2.2 | Focus Group Locations | 5 |
| 2.3 | Focus Group Discussion Guide | 6 |
| 2.4 | Focus Group Participants: General Population Groups | 7 |
| 2.5 | Focus Group Data Analysis | 10 |
| 3 | INFORMATION NEEDS OF MEDICARE BENEFICIARIES..... | 12 |
| 3.1 | Information about the Medicare Program..... | 13 |
| | Eligibility and General Program Information | 13 |
| | Covered Services | 20 |
| | Claims Processing and Costs | 22 |
| 3.2 | Information about Choosing a Provider | 25 |
| | Choosing a Primary Care Provider | 25 |
| | Choosing Specialists..... | 29 |
| 3.3 | Information about Medicare Managed Care..... | 30 |
| 3.4 | Information about Supplemental Insurance | 31 |
| 3.5 | Information about Staying Healthy | 35 |
| 3.6 | Other Information Needs | 38 |
| 4 | SOURCES OF INFORMATION | 41 |
| 4.1 | Family or Friends..... | 43 |
| 4.2 | The Insurance Companies that Pay Claims for Medicare..... | 45 |
| 4.3 | Doctors, Nurses, or Clinics | 47 |
| 4.4 | Radio, Television, and Newspapers | 49 |
| 4.5 | The Health Care Financing Administration | 51 |
| 4.6 | Supplemental Insurance Companies, Medicaid and Medicare HMOs..... | 53 |
| 4.7 | Community Resources | 54 |
| 4.8 | Organizations Such as AARP and Magazines for Senior Citizens | 56 |
| 4.9 | Other Sources | 59 |

| Chapter | | Page |
|----------------|--|-------------|
| 5 | INFORMATION MEDIA | 60 |
| 5.1 | Medicare Handbook..... | 60 |
| 5.2 | Radio and Television..... | 62 |
| 5.3 | Videos | 63 |
| 5.4 | Newspapers and Magazines | 64 |
| 5.5 | Notices in the Mail..... | 65 |
| 5.6 | Computers and the Internet..... | 66 |
| 5.7 | 800 Numbers and Automated Telephone Menus | 71 |
| 6 | SOME SIMILARITIES AND DIFFERENCES BETWEEN INVENTORY AND FOCUS GROUP RESULTS | 75 |
| 6.1 | Information Timing..... | 75 |
| 6.2 | Seamless Communication..... | 76 |
| 6.3 | Gaps in Information | 77 |
| 6.4 | Effective Communication Strategies | 78 |
| 6.5 | Characteristics of Useful Information Sources | 79 |
| 7 | SOME IMPORTANT FEATURES OF EFFECTIVE COMMUNICATION STRATEGIES | 80 |
| 7.1 | Information Content | 80 |
| 7.2 | Information Presentation | 82 |
| | REFERENCES | 85 |
| | APPENDIX A Focus Group Moderator's Guide | |

Exhibits

| Exhibit | | |
|----------------|--|----|
| 1 | Overview of Focus Group Discussion Topics..... | 7 |
| 2 | Demographic Characteristics of Focus Group Participants and U.S. Population 65 or Older | 9 |
| 3 | Mean, Median, and Mode Ratings for Amount of Information Received About Medicare and Trust of Information Sources Based on Focus Group Card-Sort Exercises | 42 |

Market Research on the Information Needs of HCFA Beneficiaries General Medicare Population Focus Groups

EXECUTIVE SUMMARY

This report is the second in a series of studies for the HCFA Market Research for Beneficiaries project. This project is designed to help HCFA better understand the information needs of its primary customers—Medicare beneficiaries—and to identify the best strategies for communicating this information to them. The project uses three complementary data collection approaches—an inventory of existing communication strategies, focus groups with beneficiaries, and surveys of beneficiary populations—to provide information that is broad in scope, deep in content, and representative of the population.

This report summarizes the findings from the first set of 12 focus groups with members of the general Medicare population.¹ These focus groups were conducted in several locations around the country. Subsequent reports will present findings from focus groups held with specific beneficiary subgroups. As with other reports from this project, the findings are organized around the two principal research questions: What information do beneficiaries want and need? and What is the best way to communicate that information to them?

Beneficiaries' Information Needs

The challenge for HCFA in meeting beneficiaries' information needs is to develop an array of communication strategies to match a broad range of beneficiary needs. Further, decisions about effective communication strategies should consider information content, audience needs, communication goals, information timing, and decision complexity.

¹ We excluded beneficiaries who are under 65 and disabled, and beneficiaries who are dually eligible for Medicare and Medicaid from the general beneficiary groups because those populations were selected as special study populations for the Phase 2 focus groups. For reasons noted below, we also excluded beneficiaries enrolled in Medicare HMOs.

Key focus group findings on the information needs of beneficiaries regarding the Medicare program itself include:

- While most beneficiaries understand some basic features of the Medicare program, others lack basic program information.
- The predominant information-seeking mode among beneficiaries appears to be situation-driven, where beneficiaries want to go to one source and get a specific piece of information related to their own current circumstances; in fact, they appear often to contact multiple sources when a problem arises.
- Specific information sources geared toward trouble-shooting and resolving contradictions could reduce beneficiary frustrations; since costly interactive communications may be particularly effective in this area, it will be important to make population estimates of the potential benefits.
- Active information seekers, while relatively numerous among the focus group participants, are a minority of the general Medicare population according to information from the MCBS; HCFA needs separate communication strategies for meeting reactive needs for specific and immediate information and proactive needs for more general information.
- Most of beneficiaries' knowledge about the Medicare program is obtained through their own or others' experience, rather than from general information like the Medicare Handbook.
- The program information needs of beneficiaries are related to their socio-economic status—more affluent or well-educated beneficiaries want more information about claims and processing, while less affluent or less well-educated beneficiaries were more likely to want basic program information.
- The needs and desires of beneficiaries for more information about claims appears related to contractor performance—the better the performance, the less perceived need or desire for further information.
- Other information needs include wanting some reassurance about the future of the Medicare program, wanting a list of available information resources, and wanting to know more about how to deal with apparent fraud.

The focus groups also explored beneficiaries needs for information about supplemental insurance, Medicare managed care plans, choosing a doctor, and staying healthy. Key findings include:

- Beneficiaries vary considerably in their understanding of supplemental insurance plans—some understand the plans well, others are able to use trusted sources to help them choose plans, and some are mostly confused by the options available to them; this last group of beneficiaries appears to need both basic general information and then specific information to help them make informed plan choices.

- Many beneficiaries feel overwhelmed by the volume of information they receive about Medicare HMOs, and would appreciate objective plan comparisons and basic information about how Medicare HMOs work.
- While beneficiaries expressed a need for objective information about choosing a doctor, including training, certification, history of malpractice, and access factors, most feel that the most important factor is interpersonal, and that they have to make the choice by trial and error, aided by referrals from other providers and from family and friends.
- Almost all beneficiaries feel that they receive enough information about staying healthy, from a variety of sources, although the information is often contradictory. There may be a role for HCFA in helping beneficiaries understand and deal with apparent contradictions.

Beneficiaries' Preferred Sources of Information

The focus group discussions examined both the preferred sources and channels for receiving information. Trust and a lack of vested interests are fundamental to beneficiaries' preferences for sources of information. Among their trusted sources, beneficiaries placed particular value on information sources that are able to distill information and present it understandably, in a timely manner, and in a way that is pertinent to their own situation. Key findings on specific sources include:

- While most participants had never heard of HCFA before the focus group sessions, they trust HCFA to provide accurate information about Medicare based on HCFA's role administering the program.
- Medical providers and insurance companies (including both supplemental plans and Medicare contractors) are important sources of information for some beneficiaries.
- Friends and family are valued information sources if they are perceived as more experienced with Medicare or if they are medical professionals.
- AARP is highly regarded by its members as a source of information, although beneficiaries are aware that AARP has vested interests in some arenas. Information about supplemental insurance is an example. Many beneficiaries joined AARP well before they became eligible for Medicare.
- The news media are not considered an important source of information, and are less trusted than other sources.
- Community organizations were mentioned infrequently as a source of information about Medicare or other topics.

Finally, the focus group discussions explored in some detail beneficiaries' thoughts about two important technological developments related to information dissemination—automated telephone response systems associated with 1-800 or other telephone numbers, and computer systems. Key findings on these subjects include:

- Almost all beneficiaries had initial negative reactions to automated telephone systems, and had limited patience for menu options or levels of options in order to get to the right person to talk with.
- Beneficiaries generally prefer to speak with a live person than to get information from automated telephone systems without speaking to a person.
- Some beneficiaries felt that telephone menus were helpful in certain situations; important features of telephone systems were a limited, clearly stated set of menu options and information on the length of the wait to talk with a person.
- Few beneficiaries felt themselves computer literate and almost none of the focus group participants had been on the Internet, although many reacted positively to a hypothetical user-friendly, accessible system for information about Medicare.

It was difficult for beneficiaries to think beyond the ways they currently get information, and when asked how they would prefer to get information they would almost invariably say “send it in the mail” or that they wanted to talk one-on-one with a person to get information specific to their needs. While electronic information media are clearly the way of the future, a majority of the current beneficiary population appears unlikely to embrace such new technologies.

Market Research on the Information Needs of HCFA Beneficiaries General Medicare Population Focus Groups

1. INTRODUCTION

1.1 Overview of the HCFA Beneficiary Market Research

As Medicare beneficiaries continue to confront a variety of changes within the health care delivery system and as information technology continues to advance, the Health Care Financing Administration (HCFA) faces the challenge of revising its operations and communication strategies in order to better serve its customers and partners. This shift will enable HCFA to address an increasingly diverse beneficiary population. In addition, general information on health insurance and on Medicare in particular has increased in volume and complexity, at least in part because the health care marketplace and the Medicare program are evolving. The fee-for-service system that has characterized the financing of health care in the United States is rapidly being replaced by a system in which health plans and other payers are managing the health care received by members. These changes will affect the nation's elderly and disabled. Many of them will be making fundamental decisions about health care programs and benefits. They will require information about the Medicare program, health care options available to them, and effective ways to use their benefits to maintain their health and to get care when they need it. In response to these and other changes, HCFA has developed a strategic plan to move the agency from an organization primarily focused on processing and paying claims to an organization that emphasizes service to its customers as the core of its mission. The HCFA market research initiative was developed to improve HCFA's service to its customers and partners and to promote effective communication strategies while incorporating innovative technologies and systems. The four components of the overall market research initiative include: (1) identifying the information needs of HCFA customers through market research; (2) improving the usefulness of HCFA data and information; (3) enhancing communication capabilities; and (4) developing formal evaluation and feedback mechanisms to ensure continuous improvement of HCFA activities. The focus group research reported here is part of the HCFA market research effort to identify the information needs of Medicare beneficiaries.

1.2 Overview of the Market Research Project on the Information Needs of HCFA Beneficiaries

The Market Research project on the information needs of HCFA beneficiaries is dedicated to helping HCFA understand the flow of information between HCFA and Medicare beneficiaries. The market research activities focus on two questions:

- What information do beneficiaries want and need from HCFA?
- How can that information be most effectively made available?

Our goal is to conduct data collection and analyses that will help HCFA understand beneficiaries' information needs and identify effective communication strategies. We are conducting three data collection activities: an inventory of information needs and effective communication and dissemination strategies, focus groups with Medicare beneficiaries, and surveys of the Medicare population. While complementary, each of the three data gathering approaches has particular strengths that will contribute to a more thorough overall understanding of the research questions. For example, the inventory research ensures that information about strategies for identifying and addressing beneficiaries' needs and preferences builds on the cumulative experience of diverse organizations involved in distributing information about health care, health care services and health care options. The focus group research is collecting detailed qualitative information from current Medicare beneficiaries. The Medicare beneficiary survey activities provide a mechanism for producing population estimates reflecting beneficiaries' attitudes toward and needs for information.

The focus group research reported here builds upon results from the inventory literature review and expert interview research activities. The goals of our focus group research were to collect information directly from beneficiaries to:

- Explore beneficiaries' perceptions of the information available to them;
- Identify information gaps that beneficiaries are aware of;
- Investigate additional information gaps that beneficiaries become aware of through discussions of their experiences;
- Identify sources of information that are particularly accessible to beneficiaries;
- Identify sources of information that are trusted by beneficiaries;
- Investigate beneficiary reactions to media and methods for communicating information about health and health care.

In order for HCFA to respond to the varying needs of a diverse Medicare population, the Market Research for Beneficiaries project will be conducted in two phases. The first phase will focus on the general Medicare population, taking inventory of broad-based communication strategies and examining the general needs of Medicare beneficiaries. The second phase will focus on subgroups of Medicare beneficiaries who may have special communication needs. These subgroups include:

- People about to enroll in Medicare;
- African-American beneficiaries;
- Hispanic or Spanish-speaking beneficiaries;
- Medicare beneficiaries who are dually enrolled in Medicare and Medicaid;
- Beneficiaries living in rural areas;
- Visually impaired beneficiaries;
- Hearing impaired beneficiaries; and
- Beneficiaries who have relatively low educational attainment.

The Market Research for Beneficiaries project will produce separate inventory, focus group and survey reports for the general beneficiary population and the identified Medicare subpopulations. The project's Synthesis Report will integrate results across the three sets of research activities, focusing on implications for HCFA communication strategies. The present document reports on results from focus groups conducted with beneficiaries recruited from the general population of Medicare beneficiaries. The next section of this report gives an overview of focus group research methods, describes the general focus group design, and gives some information about the focus group discussion moderator's guide.

1.3 Overview of Focus Group Report

Chapter 1 of this focus group report gives an overview of the HCFA Market Research project on the information needs of HCFA beneficiaries. Chapter 2 gives general information about focus group methods and more specific information about our focus group design. It includes descriptions of the focus group discussion guide, the focus group participants and our focus group analyses. Chapters 3 through 5 present our major findings. Chapter 3 focuses on results relating to beneficiaries' information needs. Chapter 4 focuses on results relating to beneficiaries' attitudes toward alternative sources of information. Chapter 5 focuses on results relating to beneficiaries' reactions to and impressions of alternative

information channels or media. We use quotations from focus group participants extensively in Chapters 3 through 5 to illustrate our main findings. The quotations are presented in text boxes to make them easy to identify. In addition, we use text box titles to highlight findings that the quotations were selected to illustrate. We used the results in Chapters 3 through 5 to identify preliminary implications for methods for communicating with beneficiaries.

We use italic font to highlight preliminary implications suggested by focus group results. Of course, focus groups with participants from the general beneficiary population are only one resource for the HCFA Market Research project. We will be conducting additional focus groups with other beneficiaries recruited from populations with special needs. In addition, our market research design includes literature review activities, intensive interviews with experts who have considerable experience developing and delivering information for Medicare beneficiaries, and surveys of the Medicare population. Given the complimentary strengths of these data collection methods, it is important to note that it is likely that preliminary implications identified here will be amplified, modified or revised based on results from the other market research components. Chapter 6 reviews similarities and differences that emerge by comparing major results from the general population focus groups reported here with major results from the general population Inventory Report. We anticipate that future reports will continue to highlight similarities and differences across methodological components of the HCFA Market Research project. Chapter 7 describes important features of effective communication strategies based on the focus group results presented here. An important goal of the project's Synthesis Report will be to identify a fully informed set of recommendations.

2. FOCUS GROUP METHODS AND DESIGN

2.1 Overview of Focus Group Methods

Focus group methods used in market research fall within the domain of qualitative research methods. The aim of focus group research is to explore participants' experiences, attitudes and motivations. Focus group research is descriptive and inductive. The goals of focus group research differ from and are complimentary with the goals of program evaluation research and survey research which are designed to estimate and evaluate quantifiable phenomena (e.g., Taylor and Brogden, 1984; Patton, 1990). The aim of focus group research is to **understand** attitudes and experiences while the aims of survey and program evaluation research are to **quantify and estimate** attitudes and experiences.

With the qualitative focus on understanding individuals' experiences and perspectives, focus group methods typically involve small numbers of participants selected according to study-specific criteria. In addition, research protocols and discussion guides are open-ended to ensure that participants report their experiences using their own words. These characteristics highlight the strengths and limitations of focus group research. Focus group methods are particularly appropriate for collecting data on individuals' experiences with Medicare in terms that reflect their own perspectives and for generating hypotheses about the experiences of individuals in different situations or from different backgrounds. Focus group methods are generally not suitable for research that requires evaluating the prevalence of particular experiences within or across populations or drawing inferential conclusions about group differences.

2.2 Focus Group Locations

The two phases of the Market Research for Beneficiaries project will involve conducting two general sets of focus groups. In the first phase, we conducted 12 focus groups with Medicare beneficiaries drawn from the general beneficiary population. In the second phase, we will conduct additional focus groups with participants drawn from selected beneficiary subpopulations with special communication or information needs. These subpopulations include: people about to enroll in Medicare; African-American beneficiaries; Hispanic or Spanish-speaking beneficiaries; Medicare beneficiaries who are dually enrolled in Medicare and Medicaid; beneficiaries living in rural areas; visually impaired beneficiaries; hearing impaired beneficiaries; and beneficiaries who have relatively low educational attainment.

The Inventory Report documented that beneficiaries in markets with early or extensive managed care penetration are likely to be exposed to different kinds of informational materials than beneficiaries in markets with later or less extensive managed care penetration. As a consequence, beneficiaries' experiences with, reactions to, and needs for information may differ depending on these market factors—even for those beneficiaries who select to receive medical care through fee-for-service rather than managed care organizations.

Given the likely impact of health care market factors on consumers' experiences and information needs, it was important to select focus group locations that reflected a range of health care markets. We considered access to selected beneficiary subgroups as additional criteria in selecting focus group locations. We conducted focus groups with participants from the general beneficiary population in 6 locations: Bethesda (Maryland), Miami, Chicago, Houston, Pasadena (California), and Hartford (Connecticut).

2.3 Focus Group Discussion Guide

When effectively moderated, focus group interactions simulate conversations that might naturally occur around a given topic. The give-and-take among group members elicits ideas and reactions that might not be revealed in individual interviews. The focus group discussion guide is an important tool in helping moderators lead the group effectively. A good discussion guide helps moderators to encourage spontaneous participation, to react to group dynamics to ensure participation from all group members, and to guide group discussion away from topics that are irrelevant to research goals while leaving room for the discussion to address unanticipated topics that are relevant to overall research goals.

We worked closely with HCFA project staff to develop an initial discussion guide and to revise the discussion guide iteratively based on additional issues emerging from ongoing inventory research activities and from early focus group discussions. The focus group agenda and discussion guide topics were designed so that the groups would spend roughly half of each two-hour discussion talking about the **kinds** of information beneficiaries want and need from HCFA and the other half of the discussion talking about **effective methods** for making information available to beneficiaries. We used a single focus group discussion guide to conduct all 12 focus groups with participants recruited from the general beneficiary population. Exhibit 1 gives an overview of the topics included in the discussion guide for the general beneficiary population focus groups, and the general population moderator's guide is included as Appendix A.

Exhibit 1. Overview of Focus Group Discussion Topics

| Focus Group Topics |
|--|
| Basic knowledge of Medicare program |
| Familiarity with HCFA |
| Recent Medicare information needs |
| Recent attempts to get Medicare information |
| Most important sources of Medicare information |
| Most trusted sources of Medicare information |
| Familiarity with and reactions to Medicare Handbook |
| Gaps in Medicare information |
| Information needs and preferred form: |
| <ul style="list-style-type: none">• Supplemental insurance• Primary care providers• Specialty care providers• Staying healthy and preventative care |
| Reactions to information formats, including radio and television, newspapers and magazines, mail-out materials, videotapes |
| Reactions to telephone resources, including automated response units (ARUs) |
| Reactions to computerized resources, including the Internet |

2.4 Focus Group Participants: General Population Groups

HCFA provided lists of Medicare beneficiaries in the six selected metropolitan areas, and focus group participants were recruited by market research firms in each area. The market research firms used the Medicare lists in combination with their own lists of research participants to identify eligible and interested participants. Early inventory results suggested that Medicare experiences and beneficiary information needs vary considerably depending on whether beneficiaries are enrolled in fee-for-service or managed care health plans. HCFA project staff decided early on that it would be counter-productive to recruit groups that mixed beneficiaries from fee-for-service and Medicare managed care plans. With only 12 general population groups, HCFA was concerned that the exploratory power of the focus group design would be diluted if half of the groups examined the experiences of beneficiaries under fee-for-service plans and half of the groups examined very different experiences of beneficiaries under Medicare managed care.

HCFA has already completed several studies using qualitative research methods to explore beneficiaries' experiences with Medicare managed care (HCFA, 1995). Based on these considerations, HCFA determined that the initial 12 groups with beneficiaries recruited from the general population should focus on beneficiaries enrolled in fee-for-service plans.

We developed recruiting procedures to identify Medicare beneficiaries who were 65 years old or older. Our recruiting methods aimed to eliminate beneficiaries who were dually eligible for Medicare and Medicaid from the general population groups because these Medicare populations were selected as special study populations for the Phase 2 focus groups and because, like beneficiaries enrolled in managed care plans, their experiences would be quite different from those of non-Medicaid-eligible beneficiaries. Recruiters were instructed to fill the groups with both men and women and a mix of ages and race and ethnic background.

Our attempts to identify dually eligible beneficiaries and beneficiaries enrolled in Medicare managed care and to eliminate them from the general population groups were not entirely successful. Beneficiaries we contacted were often not sure about the kind of health plan they were enrolled in or how their care was paid for. As a result, there were a few participants in the general population groups who were either dually eligible for Medicaid or enrolled in Medicare managed care. This report makes some observations about dual eligible beneficiaries and beneficiaries enrolled in Medicare managed care based on the few beneficiaries in these populations who found their way into the general population focus groups.² Exhibit 2 shows the distribution of focus group participants by gender, age, race/ethnicity, education, and whether they had ever participated in a focus group before. Exhibit 2 also shows these distributions for the United States population over 65 years old (Bureau of the Census, 1996).

² One group in Chicago was to be of persons dually eligible for Medicare and Medicaid. Because of confusion in recruiting about whether persons actually were covered by Medicaid, that group was re-classified as general population.

Exhibit 2. Demographic Characteristics of Focus Group Participants and U.S. Population 65 or Older

| | Focus Group Participants | U.S. Population Over 65* |
|-----------------------|--------------------------|--------------------------|
| Gender | | |
| Male | 51.0 | 40.8 |
| Female | 49.0 | 59.2 |
| Age group | | |
| Under 65 | 0.9 | N/A |
| 65-69 | 50.0 | 29.6 |
| 70-74 | 25.5 | 26.3 |
| 75 and older | 23.6 | 44.1 |
| Race/Ethnicity | | |
| White, not Hispanic | 84.7 | 86.2 |
| Black | 13.3 | 7.2 |
| Hispanic | 1.0 | 4.5 |
| Other | 1.0 | 2.0 |
| Education | | |
| Less than high school | 7.6 | 31.1 |
| High school graduate | 31.4 | 36.4 |
| Some college | 32.4 | 18.3 |
| College graduate | 20.0 | 9.0 |
| Advanced degree | 9.5 | 5.2 |
| Focus group before? | | |
| Yes | 61.9 | N/A |
| No | 38.1 | N/A |

*Source: Bureau of the Census (1996). Statistical Abstract of the United States. Education figures are for persons aged 65-74.

Compared with the U.S. population over 65, the focus group participants were somewhat younger and better educated on average. The focus group sample reflects the population reasonably well on age, race/ethnicity, and gender. Participants in all sites were reasonably evenly divided by gender. The Bethesda groups were somewhat older and better educated than those in other sites. The Bethesda groups also included a relatively high proportion of participants with previous focus group experience. The Miami groups were somewhat older and more racially mixed, the Hartford groups were more racially mixed and less educated, and the Pasadena groups had the least amount of previous focus group experience.

2.5 Focus Group Data Analysis

The basic questions this research seeks to answer are:

- What information do Medicare beneficiaries want and need?
- How would they like to get it?

The focus group discussion guide was structured to collect extensive information on both general topics, and the discussion data permit in-depth review and analysis. All 12 discussions were recorded on videotape and on audio tape. Discussion transcripts were made from the audiotaped discussions, and the transcripts were our primary analytic resource. In addition, notetakers were present at most groups to take detailed notes on discussion content and flow. Also, notetakers documented important features of the composition and dynamics in each group and drafted summaries for each group that identified important group characteristics and findings. The summaries and the video and audiotapes were secondary analytic resources. We used these materials to clarify and sharpen our analytic conclusions.

Project team members reviewed the group transcripts and summaries. Based on this initial review, we identified major themes and topics across the groups and sorted electronic versions of the transcripts by topic so that we could review what the members of different groups had to say about each general theme or topic. All quotations in the sorted transcript file were identified by group location and population, so it was possible to compare experiences and perceptions across locations. In the later report focusing on beneficiary subgroups with special communication needs, it will be possible to make some qualitative comparisons across subgroups. This focus group report discusses the general themes, experiences and perceptions that emerged across the set of 12 focus groups conducted with participants drawn from the general beneficiary population. The themes address the two general research questions, and so this report is organized around them. Chapter 3 discusses information needs and Chapters 4 and 5 discuss beneficiaries' reactions to alternative sources and communication media. Chapter 5 highlights some similarities and differences between the results reported here and results reported in the Inventory Report for the general beneficiary population.

As we discuss the themes and major findings from our focus group research, it will be clear that there are some points of agreement and a few points of disagreement between these conclusions, based on discussions with Medicare beneficiaries, and conclusions from the Inventory Report. We identify important points of agreement and disagreement in the body of this report and summarize them in the last chapter. It is important to note that our analyses were conducted separately from the inventory analyses. Obviously, the two sets of activities are not independent. Indeed, the activities were designed to inform and

support each other. It is important to note that the inventory and focus group research activities were conducted by different sets of professional staff. The use of separate staffs ensures that our focus group analyses will be receptive to new themes and messages conveyed by the beneficiaries with whom we spoke.

3. INFORMATION NEEDS OF MEDICARE BENEFICIARIES

The focus group protocol dealt with the information needs of beneficiaries in several areas: information about the Medicare program, information about supplemental insurance, information about choosing a health care provider, and information about staying healthy. Information about Medicare HMOs was excluded from the protocol because considerable qualitative research has been done on beneficiaries' needs for information about choosing an HMO and using managed care effectively (e.g., HCFA, 1995). Nevertheless, focus group participants often wanted to talk about managed care. Thus, "information about managed care" is a separate section in this chapter.³

The focus group protocol asked participants to discuss both their recent attempts to get information and the information they thought they needed but did not have. The latter approach was much more difficult for participants. It was hard for participants to talk about what they don't know. Therefore, our analysis of information needs relies more heavily on participants' reports of information they have tried to get.

Based on the focus group discussions, it appears that beneficiaries use two principal information-seeking strategies. A minority of beneficiaries are proactive, collecting and reviewing considerable information about Medicare, supplemental insurance, and other topics, out of general interest or curiosity or so that they will be prepared for whatever happens. These beneficiaries read the Medicare Handbook, attend seminars, talk with friends, family, medical providers, and others. They may read magazines, go to the library, or even check out the Internet. For these beneficiaries, comprehensive, accurate, and up-to-date information is important. They are likely to use a number of sources, and decide for themselves what information has value and what doesn't.

A larger portion of beneficiaries seek information as it is needed, in a reactive mode. These beneficiaries select sources they believe to be knowledgeable (Medicare contractors, medical providers, friends and family) and attempt to find enough information to satisfy their immediate needs. They may become frustrated if they have to go to more than one source to get the answer they need. These beneficiaries may put a premium on being able to find an adequate answer to a specific question quickly. They value easily understood information that is specific to their own situation.

³ Information about managed care was added as a focus group topic for the special population groups conducted in Baltimore and San Antonio based on comments made in earlier focus groups.

Both of these information-seeking strategies were identified in the Inventory Report for the General Beneficiary Population, which also noted that the information-seeking strategies used by beneficiaries are likely to vary depending on the nature of the health events involved. For example, the Inventory Report noted that people making decisions about forced events, such as enrollment, plan choice or acute care, may need event-specific information at the time the decision is made. People becoming aware of decisions about voluntary events may need more general information provided over a broader time frame through a variety of information channels. The context-specificity documented in the inventory report suggests that individuals are likely to adopt different information-seeking strategies in different situations.

The challenge for HCFA is to develop an array of communication strategies that will match a broad range of beneficiary needs. Decisions about effective communication strategies will require considering information content, audience needs, communication goals, information timing, and decision complexity, among other things. A goal of this report is to identify a preliminary set of effective communication design features based on input from general Medicare population focus group participants.

3.1 Information about the Medicare Program

Eligibility and General Program Information

Participants generally knew that Medicare was a government program providing health care to older Americans. With probing, participants were often able to identify Medicare as falling in the domain of Health and Human Services, but they were generally unfamiliar with HCFA and did not know that HCFA administers the Medicare program. Consistent with results documented in the Inventory report, many focus group participants incorrectly identified Medicare as a program run by the Social Security Administration. At least two factors seemed related to this misperception: (1) Medicare Part B premiums are deducted from beneficiaries' Social Security checks; and (2) information and answers to questions about Medicare are often available at local Social Security offices.

Confusion about who administers Medicare

Participant: “I get from social security [information] about the Medicare... If there’s anything they want us to know, my experience is it comes through them.”

Moderator: Okay, that’s social security, but we’re talking about Medicare, the health insurance part.”

Participant: “But it amounts to the same thing, is what I was going to say.”

Participant: “There’s an 800 number on my social security book I called.”

Moderator: “Do you know who you were talking with?”

Participant: “No. Social Security, I think.”

Participant: “(The) Social Security Administration was handling it at that time. And you called ... to find out why they weren’t going to pay for some procedure or something.”

Moderator: “That is actually the name of the agency that runs Medicare?”

Participant: “Why is it not so widely known that none of us have heard of it?”

With HCFA’s shift in focus to customer service and satisfaction, it will be important to help consumers recognize the services that HCFA provides. Accurate assessments of customer service will require that consumers make appropriate and correct attributions about provided services and information.

Most participants were familiar with some basic features of their Medicare coverage. For example, they commented on or raised questions about the relations between primary and secondary payers, Medicare Parts A and B, and the differences between supplemental insurance and Medicare managed care. However, many participants were unfamiliar with other basic Medicare features. For example, some were confused about the differences between the Medicare program, the agency who administers Medicare, the carrier insurance companies that pay claims for Medicare, and supplemental insurance companies. As another example, participants seemed confused about the differences among and relations between providers who accept Medicare patients, providers who accept assignment, and providers who are satisfied with Medicare allowable charges. In all of the groups, participants said they would like to have more information about the Medicare program, covered services, claims processing and Medicare costs. *This result is consistent with the Inventory Report conclusion that beneficiaries need descriptive information about what is covered under alternative Medicare options and about how Medicare works.*

The information that participants said they wanted differed across socio-demographic groups. Participants with low educational attainment seemed to lack basic information about their benefits and their options for additional coverage. Participants with dual eligibility for Medicare and Medicaid seemed confused about how the two programs work and especially on how they work together to cover health care benefits. Middle class and relatively well-educated participants seemed particularly interested in detailed information about their claims, their paperwork and situation-specific questions about their coverage. *It will be important to consider the costs and benefits in providing general program information that is targeted to specific subgroups. The second phase of this project will include focus groups with subgroups of the Medicare population identified as having special communication needs. If this theme recurs in the Phase 2 focus groups, then results from the second phase will be useful for exploring cost effective methods for providing and distributing targeted communication.*

Participants generally agreed that they have learned about Medicare processes and procedures by experiencing them. This theme recurred in several contexts, including learning to ask (and learning how to ask) about whether doctors accept assignment, learning about payment processes, learning about cost structures, and learning how to work with primary and secondary insurers to pay for health care services. *Providing more effective and more targeted descriptive information may reduce frustrations beneficiaries feel in learning through experience. Reminding beneficiaries that experience will be a valuable aid and that other resources are also available may make it easier for beneficiaries to learn effectively from experience.*

Participants generally learn about Medicare by experience

“Well, I’m fairly new. I just started in February. I have found that I don’t really know what’s going on... some of the doctors don’t charge me anything... Some of the doctors make me pay... It’s very confusing to me.”

“What I finally figured out is, most of the doctors send it to Medicare. Medicare sends it to [my supplementary insurance] and then whatever didn’t get paid, the doctor bills me for.”

“She called the doctors office, asked if they accepted Medicare assignment. Whoever she talked to said yes. So we learned our lesson. After this it’s going to be who said that and put a time and a date.”

“So you have a hard time knowing which is which... At first. You learn after several visits.”

“It all is a function of whether or not the auditing staff understand the legal terms that are being used on these forms... accept assignment has a specific legal meaning. Allowable charge has a specific meaning. And we have to learn the hard way right now because there is no reference to which we can go that will give us the meanings so that we understand the terms... used in the whole billing process.”

“You have to ask... You ask him, does he take assignment... You learn to ask...”

“I went to Social Security or something like that. She said, ‘Don’t you ever pay first...’ She said, ‘You never get back the amount that you should get....’ I heard that. I’ll always remember that.”

“I needed more research. So, I just took the low Medigap insurance because I didn’t have to make the payments on it. That was a mistake and then the only one time eligibility that I had, I couldn’t be reinstated. That’s what I’m stuck with right now.”

Participants reported that their recent experiences seeking Medicare information were often motivated by problems they were having getting care, getting their care paid for, or meeting Medicare reporting needs. The quotations in the box below illustrate the different perspectives of participants who were frequent and less frequent users of their Medicare benefits. This feature of beneficiary information seeking is important because it means that active information seekers are likely to be looking for targeted information that addresses specific (and immediate) needs. *Active information seekers are likely to be looking for specific information. HCFA might benefit from developing two communication strategies: one to address specific and immediate needs and another for distributing more general information.*

Information needs differ for people with different health care needs

Infrequent user: “Now again, I haven’t had any complicated surgery or anything like that, so it could be complicated at some stage of the game. But it hasn’t been. Three months before I became 65, they sent me a letter saying everything is okay... I got the card. Everything was fine. It purrs like a machine.”

More frequent user: “Unless you have a serious illness and then they don’t want to pay for certain things and you’re going back and forth. I had a lot of problems like that with my dad and my mother.”

Some participants reported situations where they were able to obtain information and resolve questions about coverage or claims easily by contacting appropriate resources. Others reported circumstances where they obtained information or resolved confusion about coverage or payment processes by contacting a resource who was willing to advocate for them. Participants’ comments suggested that these advocates were more likely to be found through trial and error or serendipity than through official channels of information.

Resolving questions by contacting appropriate resources

“We got a letter saying we were responsible for a certain amount, which wasn’t true. First we called the doctor and ... he said he had nothing to do with it and then we called the Social Security (office) and they straightened it right out.”

“Many times when the Medicare doesn’t approve of it they put a note on it and tell you why and then I usually call the doctor and make sure that they filed it correctly.”

“Sometimes you get a call and you call doctor’s office and they tell you well we never filed a claim. We just over looked it.”

Finding an advocate by trial and error

“Well on the case that’s doubled charged ... we finally went over to the Social Security office.... We didn’t want to call, but he gave us (an address) that you could mail to. So we ... wrote our correction and sent it in.... And it was mailed back very rapidly. Very rapidly.”

“ The rules state that ... they are supposed to pay it so long as that letter is accompanied with that claim... they claimed in our case that they never received a letter..... I volunteer at the hospital so I know some of the people there. And I went down to one of the girls who handles it and I explained the situation. She said leave it with me and I will take care of it. Now how she did it I don’t know but she did get it taken care of in her own way.”

“When the cardiac man said you need.. a new drug, not covered, somebody steps in... The cardiac man said “I’ll get in touch with the pharmacists” and the pharmacist called some kind of number...”

“(The) hospital helped me with my mother and dad. I didn’t know anything about it. They helped and the doctor helped.”

“Someone made a mistake somewhere and gave someone else my social security number. I got all the paperwork for someone who had open heart surgery. I immediately called Medicare first. Then my [supplemental] insurance because I didn’t want them putting money out.... Somehow by getting hold of this person’s doctor, the person who had the surgery, I got his social security number and ... [it] was very easy to see that they had transposed two digits. It went on for a long time. I didn’t give them credit for any brain miracles.”

Participants who reported receiving conflicting information about Medicare coverage or procedures were frustrated by the contradictions and confused about how to resolve the conflict. They were not always sure who the final authority was and they seemed to feel caught in the middle of interested parties who were making competing claims. *Specific information sources geared toward trouble-shooting and resolving contradictions could reduce frustrations. Potentially costly interactive communications may be particularly effective in the area of troubleshooting, so it would be useful to get population estimates of beneficiaries’ perceptions of and attitudes toward the potential costs and benefits.*

Several participants expressed confusion about procedures and terminology related to allowable charges and assignment. The differences between “accepting Medicare patients,” “accepting assignment,” and “allowable charges” led participants to recommend that HCFA develop a glossary of terms to help beneficiaries understand what information resources are saying.

Confusion about allowable charges and assignment

“‘Accept assignment’ has a specific legal meaning. ‘Allowable charge’ has a specific meaning. And we have to learn the hard way right now, because there is no reference to which we can go that will give us the meanings so that we understand the terms that are being used in the whole billing process.”

“A lot of people hear the word ‘assignment,’ and yet they can’t define what that means. But it does tell you [on the explanation of benefits form] that if a doctor accepts assignment, that means he’s willing to accept as full payment 80% of Medicare’s approved amount.”

“As I understand it, he can’t charge you more than the additional amount... I’ve never been clear ... how it works.”

Some participants were aware that HCFA provides information about terminology and procedures. For example several participants mentioned using the Medicare Handbook as a resource, and others noted the Explanation of Medicare Benefits (EOMB) form provides information about processes and procedures. At the same time, many participants did not seem to recognize that there were existing resources to answer the questions they were asking about Medicare conventions and procedures. *Expanded and simplified Handbook glossary materials could be packaged and distributed in several ways to address particularly frequent sources of confusion. For example, glossary definitions might be included as a section at the back of the Medicare Handbook. Particularly important or particularly confusing terms might also be defined in the handbook text where they are introduced, perhaps in marginal notes. The Handbook glossary materials might be printed separately as a brochure that could be distributed to beneficiaries who have questions by counselors at social security offices or at other counseling agencies or by staff who work at toll-free telephone information centers. The same information might be made available through Internet sites as they develop, and additional claims-specific glossary information might be included on the EOMB form. As alternative formats are developed, advertising communications will be necessary to ensure beneficiaries are aware of the resources available to them.*

Covered Services

The Medicare Handbook is one general source of information about Medicare covered services. Roughly two-thirds of the participants recognized the Medicare Handbook and said they received it and reviewed it. Several beneficiaries reported using the Handbook as a reference resource, but few reported using the Handbook regularly. The Inventory Report noted that beneficiaries are most likely to consult their Medicare Handbooks when they need specific services. (See Chapter 5 for more on the Medicare Handbook.) The quotations in the box below illustrate the kinds of general information beneficiaries would like to receive about their coverage. *Some of these topics might be addressed once in Medicare orientation materials. Other topics would require ongoing communications, possibly in coordination with supplementary insurers and Medicare managed care providers.*

Questions about Medicare coverage

Participant 1: “Medicare should send out flyers to each participant... a listing of what is actually covered.. what they can get and what they can’t get so we know where we stand... What we have and don’t have.

Participant 2: “Well, you can get that through the social security office.”

Participant 3: “They also have booklets that they can send you... Anything you want to know, just call social security and they’ll give you the number.”

“But today when you get a booklet, it’s a waste of time reading it, because it changes next year.”

Participant 1: “I think it would be a good—an extremely good idea for... the government to keep us posted, maybe not by the month, but yearly, on the different benefits we can take advantage of or look for with our Medicare coverage.”

Participant 2: “I think that would be wonderful... How do you know what the changes are, unless they point it out to you? And I just give up.”

“I didn’t understand a lot of what Medicare covers.”

“Well, they might go down... examples... and run through, step-by-step, on how things should work.”

Participants’ experiences with hospitals and other special kinds of care highlighted the importance of timing in delivering information about covered services. The Inventory Report also identified timing as an important component of effective communication about Medicare. As illustrated by the quotations in the box below, beneficiaries were particularly grateful for information they could use proactively, and they were frustrated when they learned about coverage limits after receiving services. The quotations below also illustrate that some beneficiaries find their doctors are effective advocates, helping them get needed services. Other beneficiaries are confused by the information their doctors provide about Medicare coverage.

Finding out about Medicare coverage: Information timing

Proactive information

“I just recently went through surgery... [The hospital] referred me to a social worker who explained to me what I was entitled to... Somebody told me to be sure and get that straightened out first...And the hospital was very good... In fact, they had a session before you went into the hospital... to explain what was covered and what wasn’t covered.”

“I discovered this the hard way when I retired ... discovering that I was already subject to Medicare... I had no information from [Medicare] prior to that time. I was in the hospital [for] surgery ... I thought that the federal health benefits program was the primary payer, and it wasn’t... then I became acutely aware of the price differentials... There is no single source of information on it.”

Participant: “I had to have a ... diagnostic stress test ... [My doctor] wanted to call Medicare and see if I was eligible for another one so he did and I took it and Medicare took care of it.”

Moderator: “Okay, so the doctor actually called Medicare?”

Participant : “Yes, he said he had to call Medicare before I could get the approval to have it done. “

Information “after the fact”

“My wife needed therapy and ... I listened to the doctor which is probably mistake number one. He says don’t worry you are covered by Medicare..... We went to the hospital for the therapy that she needed and when it came to pay, the hospital sent me a bill that was larger than what Medicare paid.... They said that Medicare pays 20 percent of what the hospital bills.... In other words, the hospital billed \$1,000, Medicare approved \$500, they paid 80 percent of the \$500. I was billed 20 percent of the full \$1,000.”

“So, when I got 65, they just sent me the letter. I was switched over to Medicare. I guess Medicare sent me the forms or whatever... I really don’t know how I got into it. They should have explained to me what Medicare was.”

“I got some information quite by accident. I’m a diabetic and I was at the pharmacy... The woman in front of me was getting the little tags they use for when you take your blood. Those cost about \$35 for 50. The woman in front of me was getting [the strips] for 80% off... In other words it cost her, maybe \$8. I asked the pharmacist... why did she get a discount. [The pharmacist] said... if you’re on Medicare you automatically can get it at that price. I didn’t know that. There is a lot of things I don’t know about Medicare... I mean what I’m entitled to or what I can get and what I can’t get.”

Several participants raised specific questions about covered services, including changes in coverage for mammograms, coverage for prescription medications and devices, and payments for specific treatments. These questions are consistent with the Inventory Report finding that beneficiaries often do not recall or understand their coverage and these questions suggest that participants are not sure how to find out answers to detailed questions about covered services.

The most effective information is that which can be used proactively. However, simply providing a general reference like the Medicare Handbook is not sufficient to give most beneficiaries this advantage. They need some external method to relate information to their needs. Doctors and other providers who are given correct information and who are effectively motivated to share it with patients can be an effective source of proactive information about Medicare.

Claims Processing and Costs

Participants who were satisfied with the way their claims are processed generally said they did not need much information about Medicare claims processes. They seemed to think the system worked fine without their involvement. Participants who were less satisfied with the claims services seemed to want more information and more involvement in Medicare payment processes.

| Perceived need for involvement in claims processes depends on satisfaction with claims procedures and outcomes | |
|---|---|
| Satisfied with Claims Processing | Dissatisfied with Claims Processing |
| <p>“But not everybody is unfortunate in requesting a claim. We had a two year old claim through the (supplemental) insurance company...It was settled and it didn’t take too long... It took two years for it to come back to us but it was settled right away.”</p> <p>“When you go to a doctor’s office... they say, ‘let me see your card,’ they copy the number down and you don’t hear anymore unless there is a problem. So, it’s relatively simple.”</p> <p>“Fortunately the doctor that I go to... takes the assignment.... He does all the paperwork, so that there’s nothing for me to do but wait for the... return... So that way is easy for me.”</p> <p>“I used the Medicare quite a bit the last few years and I’ve had no problem. Everything just goes through. No problems at all.”</p> <p>“It’s fairly smooth, actually. I’ve gone through some major [medical conditions]... and haven’t had any problems.”</p> | <p>“But the problem, again, is lack of information in terms of accessibility to the patient. The provider and the payer may know what they’re talking about, but the patient, in most cases, hasn’t the foggiest notion of what the arrangements are... I think we have to have full disclosure. We need to know what’s going on.”</p> <p>“I think everybody around this table has been confronted with a huge paper trail... there are at least three levels of processors... the medical people are fighting back and they are angry ... And the patient is caught in between.”</p> <p>“How many of you feel like you have had to intervene in the claims process to make sure things were handled correctly?”... “All the time”... “Yes”... “Not in all cases, but at certain times.”</p> <p>“You really have to be responsible for yourself...And if you’re not gonna be responsible for yourself.. you know you can end up in big trouble.”</p> <p>“You have to be so responsible. In other words you really can’t rely on this one or that one, you must watch yourself with your billing, your medications and everything. You can’t just say, ‘they’ll take care of it’. It don’t happen that way.”</p> |

Participants had mixed reactions to information provided on the EOMB form. Some participants reported that they are consistently confused by the paperwork associated with their benefits. These participants mentioned the Medicare codes and the volume of paperwork as sources of confusion. Other beneficiaries reported that the EOMB forms are valuable in helping them to keep track of the services they received, claim status and payments they owed.

Confusion about claims processes and paperwork

“The information sheets that are prepared by computer are absolutely obscure... They use terminology that there’s no dictionary for. There’s no glossary provided. And the syntax they use is archaic.

“When I get one visit to the doctor... I will have a great big stack of paper that I’ve waited and put notes on..... And it takes a long time before I get down to that last thing where the doctor tells me I still owe him \$9.29.”

“I think everybody around this table has been confronted with a huge paper trail, and an auditing nightmare.”

Satisfaction with claims processes

“I had bypass surgery and I handled all my paperwork... Well, I think that at last count, my bills were two inches thick... But if it weren’t for the Medicare Explanation of Benefits, which I think are wonderful, I could not nail down the providers when they make errors ... I Xeroxed Medicare Explanation of Benefits and say, Haven’t you looked at this? ... I want to applaud them.

“Without it, I think we’d all be lost.”

“I would almost say the same thing. If you follow the rules, everything is really simple. But you can make it awfully hard if you’re not careful.”

“There’s a sign... we must submit your Medicare statements. They submit and I get the form back. If ... they don’t pay it all, I’ve got to make it up. It says plainly on there that your doctor has a right to charge you for whatever we’re not paying for... It’s on the pamphlet, bill or statement you get from Medicare.”

Some beneficiaries feel it is important for them to understand and monitor claims processes for their Medicare benefits. These beneficiaries actively sought and were happy to receive detailed and technical information about care they receive and how it is paid for. Other beneficiaries prefer simpler information that functions to reassure them that the Medicare system can operate without involvement or input from them. Layered communication strategies could be effective for providing information about claims and claims outcomes since the aim of layering is to help beneficiaries identify and get the level of detail they prefer without having to work through information they don’t want. The recently redesigned EOMB form might be the most detailed layer in a communication “package” that helps beneficiaries get to the EOMB if they want to and avoid it if simpler information is sufficient.

3.2 Information about Choosing a Provider

Choosing a Primary Care Provider

Participants identified several kinds of information that would be useful in selecting a primary care provider, including training, medical school attended, and certification status. Some participants knew they could get this kind of information from hospital referral lines, medical associations and reference books. From participants' comments, it was not clear that they would know how to use this information to select a primary care provider. In other words, it seemed that participants believed information about a provider's credentials and experience would be related to the quality of care available from the provider, but they seemed more comfortable relying on more familiar kinds of information to select their own providers.

Some examples of familiar types of information that participants mentioned as useful resources included: recommendations from other trusted providers, recommendations from friends and family, or personal experiences with a provider. These findings agree with results reported in the Inventory Report indicating that consumers think of quality in terms of their own experiences with access, waiting and communication.

Resources for information on primary care providers

Participant 1: "I've used the library quite a lot.. [looking for] where they got their degrees, what their age is.... Usually you can narrow it down to four or five names in a particular location... I don't want to be driving..."

Participant 2: "But I think [you are] probably a little more analytical.... Most of us have gone by referral, built upon the trust we have with our initial provider."

"I think you must have someone on the medical profession that you really have confidence in. Then you can go to him and start there.... I called my original doctor.... I think you have to have somebody in the profession ... We don't know enough to make a decision."

"I find this book in the library... the Directory of Medical Specialists ... and you can go look up by the state and then the specialty.... It gives you a good profile of the doctors. That's not always the best way, but at least its something to help you make a decision."

"I call the 800 number, doctors, 1-800-doctors. And I wanted a doctor for senior citizens, was interested in senior citizens that was in my area... I wanted a family doctor... Well, they gave me some names of some doctors that [were] about 10 or 15 miles away. They told me what schools they went to. They told me what languages they spoke. They told me where they were born. And everything that I wanted to know."

Personal experience with primary care providers

"If someone gave me a list of doctors... some information on a list of doctors, I still wouldn't know which one to pick until I got right down to the nitty gritty and talked to him."

"But besides his education you want to know if your personality jives with his.... More about his philosophy. I guess you may want to start by checking with your friends."

One of the most frequently mentioned resources for finding new providers was recommendations from other trusted providers. Recommendations from friends and family were also a frequently mentioned resource. With probing, participants identified shortcomings with both of these resources. For example, participants noted that they would not necessarily want to ask their doctor to identify someone to give a second opinion about a major decision. In this case, participants would be interested in an independent opinion.

Trusted sources of information on primary care providers

“We’ve had one doctor for 44 years and we still go to him. Any surgery or anything like that, I trust him to select the doctor for me. I’ve never had any problem with that.”

“Most of us choose a particular doctor, initially, because some friend or somebody that we know recommended that doctor to us. Then after we go to that particular doctor, if we’re satisfied or we think that he fits the bill that we’re looking for, we stay with them. If not, you go elsewhere. “

“You go to your friends who have been dealing with a doctor for quite a few years. Find out ... what kind of a doctor is he..... If [they are] good friends, then you trust [them].”

“A lot of hospitals give you information. They will recommend several doctors so you take your choice.”

Difficulties relying on a single source of information about providers

“You ask a doctor that you already use for his... But it’s not always satisfactory because they have friends... so you don’t know you’re getting the best.”

“Most of the doctors... are on the staff at that hospital. And that’s what the hospital will give you. Any hospital will do that.”

“And when you ... [go] from one doctor to the next you get the same mentality, the same type of background and education that the other one had ... without getting say an update or a younger person with a more liberal type of approach to an illness.”

The quotations in the box below illustrate some of the factors participants mentioned in selecting a provider. Participants reported that interpersonal factors, such as ability to communicate with patients and willingness to listen to and spend time with patients were especially important in selecting a primary care provider. Participants generally agreed that the best way to get information about a provider’s interpersonal skills is through trial and error. A few participants reported that they would feel comfortable interviewing a provider they were considering, but this strategy was mentioned infrequently. Participants discussed other important provider characteristics, including convenient location and hours, ability to make appointments for sickness, experience with aging patients and follow-through. Participants also identified a provider’s record as an important factor that they’d like information about. Several participants currently looking for new providers said they were concerned because they do not know how to proceed.

Interpersonal factors in selecting a provider

“How does he speak with you? ... Does he speak down to you? Does he talk plainly to you so that you understand what’s going on? And if he’s not adequate to treat your particular problem does he ... recommend somebody else?”

“See I don’t know that people could get information about a doctor in this type of a book. You would have to have experience with the doctor. I don’t know that they would be able to put it down in black and white. I think each person will need a certain type of doctor. Some people want doctors that are serious. They don’t want joking around.... Then some other person would want to make that person feel at ease. I just think it depends on the patient.”

“My daughters told me last week... they said, ‘Mother. Where have you been? All you have to do is call a doctor’s office; ask for an interview.’”

“But there are some questions that you can’t ...ask. If you did ask, they couldn’t tell you. For example ... it may seem small, but ... a major one [is] bedside manner. Some of these people can’t communicate. Some have dollar signs instead of brains.”

Other provider characteristics

“I’m getting on in years. The thing that perhaps is most important is to find someone who understands geriatrics, because you go to some younger doctor ... and he’s dealing with ordinary run of the mill-type stuff and here you’re an old coot... [the doctor] doesn’t necessarily know.”

My wife says... [her doctor is] very thorough. She gets tests made and she’ll call the next day to tell my wife what the tests were.... Real follow through. Those are the kinds of doctors that I want.”

“I read a magazine and there was an article about what you should really do in choosing a doctor... there were ten or twelve questions that you ask the doctor. When it comes to health care, the more you read yourself, the better off you are.”

Provider’s record and past performance

“I would like to know if he’s had any lawsuits against him and what his record is. I don’t think there’s any way we know if a doctor has been investigated by Medicare because he has put in claims that weren’t truthful... We don’t know these things. We don’t know if a doctor has had twenty malpractice suits against him.”

Difficulties getting started finding a new provider

“We don’t know enough... [Someone] asked me why I didn’t leave the [doctor]... that didn’t get the swelling down in my foot. Basically, I didn’t know where to go.”

“It’s a very difficult thing to find a new doctor. Our doctor retired and he sold his practice to another doctor. I go to him now, but I’m not completely satisfied. I don’t know where or how to go about finding another doctor. That would be very difficult to do.”

“I spoke to a lot of friends, acquaintances, trying to find someone who might be worth trying. Through trial and error I finally found someone who I like.”

Many participants were comfortable relying on their own judgment, on their social networks, or on referrals from trusted sources to help them find a provider they like. It seems that a smaller number would prefer stronger guidance in finding a primary care provider.

Choosing Specialists

Participants reported that they rely on their primary care providers to help them identify specialists. There was strong agreement on this point across participants and groups.

Primary providers are frequent resources for finding specialists

“I think that ... if you trust your primary care doctor. He is the one that’s going to refer you to the specialist.”

“I don’t think you have another choice unless you go out on your own. What do I know? Why wouldn’t [my primary provider] refer the best [specialist]? He knows.”

“He’s been my doctor for 30 some years. He does know a lot of other doctors. He makes all the referrals when I need something special.”

“A primary physician is like the quarterback... what he doesn’t know, he sends me to [other] people.”

“Start with your primary care physician. And you’re referred to a doctor. After all, he’s in the business. He should know who is good.”

3.3 Information about Medicare Managed Care

Focus group recruiting efforts largely screened out beneficiaries who were enrolled in Medicare managed care programs, and the focus group protocol did not directly address information needs related to HMO's and Medicare managed care because several recent focus group studies explored these issues in depth (HCFA, 1996). However, several of the groups raised questions about Medicare managed care. It is possible to determine some information needs from these spontaneous discussions.

When asked, participants generally agreed that HCFA could play an important role in explaining the options available to beneficiaries and how Medicare managed care works. Participants reported that they receive volumes of material from individual managed care plans and they would like a single source to summarize the plans and provide materials to help beneficiaries compare the benefits and costs of alternative options, including both managed care and fee-for-service options. Some participants noted that the materials they receive from Medicare managed care plans do not provide sufficient detail about how managed care systems are structured financially. They reported that detail about managed care financial incentives will help beneficiaries select and use their plans more effectively.

Need for information to understand and evaluate Medicare managed care options

Moderator: "What kind of information would you like the [Medicare] program to provide?"

Participant: "How ... Medicare would be compatible with the ... HMO's... payment and service.

Participant: "Chart ... at least the HMO companies—a comparison of coverage.... straight down where you could look at it and read. A lot of times you would have to go through three or four or five articles.... You forget what you have really looked at."

"People come into your home and they talk to you but they do it so hurriedly... and only in the interest of the HMO plan... They can really sell you a job if you aren't careful. "

"I'd have to really find out a lot of answers ... whether it's advantageous to change to an HMO. It's not as easy as you think.... By the time I get all that literature I'm so mixed up I don't know."

Participants mentioned a few features that made Medicare managed care seem attractive to them, including lower cost and more extensive coverage in some areas such as prescription medications and vision care. Participants also mentioned features that made Medicare managed care seem less attractive to them, including concerns about access to doctors and restrictions on provider choice. In addition, participants noted that their own doctors' participation in Medicare managed care plans is an important factor to consider.

Attractive and unattractive aspects of Medicare managed care

“I find out [my doctors are] affiliated with two HMO plans. I’m getting some thoughts as to whether I should switch over to one of those [Medicare managed care plans] and still have the same doctor... So, I’m thinking about it. “

Participant 1: “There are a lot of complaints from people who are on HMO’s that they can’t get in touch with the doctors, the doctors don’t call them back. The nurses just put these patients off....

Participant 2: They connect you with the nurses’ desk and when they connect you with the nurses’ desk, that’s as far as you get.”

“I have friends that belong to ... HMO’s and they wait weeks if not months to get a specialist that they might want.”

“My thing is I wanted to keep Medicare because this way I have a choice even if I pay the difference sometimes.”

“I like the choice of being able to select my doctor, select my hospital.”

“Concerning HMO’s.... they have a tendency... to get you out of the hospital just as quickly as is humanly possible. Maybe even a little quicker.”

When asked, participants generally agreed that HCFA could play an important role in explaining the range of options available to beneficiaries and how Medicare managed care works. This result is consistent with other focus group results on information for making decisions about and making effective use of Medicare managed care (HCFA, 1996).

3.4 Information about Supplemental Insurance

Discussions of information about supplemental insurance revealed at least three general groups of participants. Some participants seemed to understand their Medigap options and how to get information about supplemental insurance. These participants said they understood the lettered supplemental plans and the trade-off between coverage and cost under the plans. These participants also seemed to understand that once they’d selected a supplemental plan, the choice of insurance company should be based on cost.

Participants who understand their options for supplemental insurance

“I had at least 3 companies that I was deciding from. I had all the information that I needed. They all send you charts. They tell you precisely what it is. The cost for Plan A through Plan F I believe it is or Plan G. These are all Medigap programs... So because the government has said you can only have A-F or G plans to offer, and they’re all exactly the same, the only difference is the price. Therefore, the choice is comparatively easy.”

“They’re all alike. You can go to one company and another company, and they’re all alike. It’s just a matter of service and price. They’re not going to tell you that though... they’ve all got A’s and they’ve all got B’s and all that. And they all are identical. There’s no difference between any of them.”

“Every insurance company has to offer identical plans, do they not? So if you are choosing between the plans, you’ll get the same thing.”

A second group of participants seemed less knowledgeable about the details of supplemental insurance, but they had identified knowledgeable and trusted sources who were able to give them advice in choosing and using supplemental insurance. In many cases, the trusted source was an employer, and in some cases it was an insurance agent.

Participants who rely on a trusted resource for advice about supplemental insurance

“I think [my employer’s plan] sent a letter to me before I became 65 and said, ‘If you retire from the government and you keep this insurance, then we will agree to pick up ... all of the things that we would normally cover, that aren’t covered by Medicare’ ... if you’ll keep this and not just go get some Medigap insurance somewhere else.”

Moderator: “... Who would have liked more information?”

Participant: “I would have... At the time I just took AARP because a friend of mine had it. Nothing else was ever explained to me.”

“I researched all my friends that were 65 and older to see what supplemental coverage they had and asked them for their honest opinions of what they thought of their plan. I think of about 10 people that I discussed it with, the majority took AARP and were very happy with it. That’s what I went with.”

“A friend of mine whom I trust. He researched my company pretty well and then I checked with my agent and he said it was a very good company and I bought it.”

“I went to AARP and I said what is your best plan. What do you think is the best?”

“I called my insurance agent.”

A third group of participants seemed confused by supplemental insurance. These participants did not seem to understand how Medigap insurance policies fit together with the Medicare program, and they seemed confused about the differences between supplemental insurance and Medicare managed care. They described information they received about supplemental insurance, but they seemed unsure about who the information came from—whether from insurance agents, from the Medicare program or from Medicare managed care companies.

Participants who were confused about their supplemental insurance options:

“When I first was eligible, I knew that—or I thought I needed... some kind [of] supplemental. So I took one out with [an insurance company]... And here was the exact duplicate of the [insurance I got through my employer].”

“I don’t know if I had a choice. I don’t know how I got [my supplemental insurance]. I really don’t know.”

“I needed more research. So, I just took the low Medigap insurance because I didn’t have to make the payments on it. That was a mistake and then the only one time eligibility that I had, I couldn’t be reinstated. That’s what I’m stuck with right now.”

The information needs for these three groups of beneficiaries are very different. Existing information channels seem to be working effectively for the first group of participants who understand how supplemental insurance operates. The second group of participants who rely on trusted resources requires specific information they can use to answer particular questions as they encounter them. It is also important to note that people who rely on trusted others may require more extensive information when trusted others become either temporarily or permanently unavailable. The third group of participants requires basic information about the Medicare program, the structure of Medigap supplemental insurance and the relations between fee-for-service and managed care options available under Medicare. Once this third group of participants has access to basic information about supplemental insurance, they will also need more specific information they can use to answer particular questions as they encounter them. As noted in the Inventory Report, it is important to make this information available in several forms and from a variety of sources to fit with a range of information-seeking habits and practices.

Participants commented on the complexity of the choice of a supplemental insurance policy. In addition, information timing seemed especially important to beneficiaries making decisions about supplemental insurance. Some participants spoke clearly about the kind of information they wanted. The quotations in the following box illustrate these points.

Decisions about supplemental insurance

Complexity

“We made the choice simply because we were being defensive about it. I have Medicare A, I have Medicare B, and I have a secondary payer. And I’m not sure that I might be double paying, but I haven’t got a single document that I can go to that can tell me that I have all the gaps covered.”

“It’s not simple. You have to be a Philadelphia lawyer to understand all the claims.”

“Well three different agencies give you three different [answers].... If it’s the same insurance why shouldn’t all the answers be similar?”

“I think that there’s more than enough information out there. It’s just so confusing you just don’t know what to do.”

“This other fellow and I ... he researched some of it, I researched some of it and we swapped notes... He talked to different people. I talked to different people. I called my doctor.... I felt we did a good thorough research, but it took 8 hours a day for a week.”

Timing

“I think [my employer’s plan] sent a letter to me before I became 65 and said if you retire from the government and you keep this insurance, then we will agree to pick up... all of the things that we would normally cover, that aren’t covered by Medicare.... I feel like they made me the offer if you’ll keep this and not just go get some Medigap insurance somewhere else. Then this is what we can do for you.”

Information needs

Moderator: “You want to see it like in a handbook form?”

Participant : “Right... but simplified... Without language that most people do not understand... simple one, two, three. We cover you this, this and this ... and we won’t pay other things and then you know where you stand.”

“I chose Blue Cross. They had a chart showing what they cover, the cost [compared] between themselves and other insurance companies.”

Participants mentioned several specific questions related to supplemental insurance for which they would like more detailed information. Some examples are: insurance rates across insurance companies, information about any restrictions on provider choice, and requirements for a second opinion. *Layered communication strategies may be particularly important in the complex area of supplemental insurance. It may also be important to present information in a variety of formats to meet different searching and learning styles. For example, some participants preferred printed brochures, some preferred graphical displays like charts and diagrams, and others mentioned group discussions as effective means for collecting and synthesizing information.*

3.5 Information about Staying Healthy

Participants generally agreed that they have access to plenty of information about preventive care and things they can do to stay healthy. Some participants emphasized that individuals have to show initiative and take responsibility for getting the information, but relatively few participants from the general beneficiary population reported that they do not get enough information about ways to stay healthy and preventive care.

Availability of information about ways to stay healthy

Moderator: “Okay, we’ve talked about choosing a doctor, how about staying healthy? Do you get the information that you need to stay healthy?”

Participant: “That is everywhere.”

“The more that you read about it, the worse you feel. But it makes you aware....So I think it’s good to have the information and newspapers and magazines and stuff.”

Moderator: “Do you get enough information on ways to stay healthy?”

Participant 1: “Yes I think we do.”

Participant 2: “ Oh yes, I’d say we definitely do.”

“Well, with us males, there’s prostate cancer. I think the more information they can give me about it the better I’m going to feel.”

Role of individual initiative

“They give you pamphlets.... they give you papers that you can read up on. It’s very interesting. You have to do your own—you have to assume some responsibility. You can’t have somebody hand feed you.... If you don’t speak up, you don’t get the proper information. So if you don’t take responsibility, you don’t get any of it.”

Participants mentioned a variety of sources of information about things they can do to stay healthy. Sources mentioned included Prevention Magazine, Modern Maturity from AARP, other publications developed for senior citizens, regular health sections in newspapers, regular segments on radio and television news programs, flyers provided in hospitals, doctor offices and libraries, classes provided by hospitals, booklets published by HCFA, and lists of publications maintained at community centers. Participants also described valued reminders they receive about getting preventive care, including reminders on the EOMB form and reminders sent along with social security checks. Several participants reported that their doctors were primary sources of information about how to stay healthy.

Value of reminders about preventive care

Moderator: “So it sounds like you appreciate being reminded?”

Participant: “Yeah.”

“I don’t remember about the flu shots. I think that’s in the Fall.... [There is] ... something in the mail that we get, I can’t remember if its with the social security checks about the flu ... shot. That’s always, I think, a good idea. It reminds you...”

“I think it’s good. We recently got a statement from Medicare and there was a little paragraph in there and it said that we should be getting our flu shots.”

Resources for information on ways to stay healthy

Moderator: “Do you feel like you have enough information about preventive care?”

Participant : “If you have a doctor you can trust, yes.”

Moderator: “What’s the best way to get that kind of information?”

Participant: “Call you doctor....From your doctor, [information] on what you should eat and what you should not. What you should do. Exercises you should take.”

“The doctor advises me and I got the pneumonia shot and the flu shot.”

Some participants seemed frustrated or confused by conflicting information they find about how to stay healthy. Other participants reported that they had trouble reconciling research results with their own experiences.

Frustrations with conflicting information about ways to stay healthy

“Eggs are not good. Eggs are good. Eat more eggs. Don’t eat eggs. It is back and forth.”

“So you know, I just don’t know what you should believe.”

“One minute they say one thing and they retract it. I stick to my doctor. I mean I go to him for check ups two or three times a year and he tells me if there is anything or what I should do about it. “

“There’s a lot of information. I wish there was some governmental agency that would discern which is good and have some [statistics] ... on how it comes about.

Participant 1: “I was going to say, what was healthy for you when you were a child, is now deadly...”

Participant 2: “Each month the standards change.”

Participant 3: “Coffee was good, now it’s no good. Now it’s good.... Just like margarine and butter... You don’t know what to do.”

“Well, who do you trust? I mean you get so many periodicals and everyone seems to differ from one another and I just think you have to get all the information you can and then separate it.”

Difficulty integrating research on and experience with ways to stay healthy

“I’m thinking my own parents, both of whom lived into their nineties. They eat anything they want to. In fact, if you cut the fat off the roast for her, she’d say no give me that that’s the tastiest part. And she lived to be 93 for heaven’s sake. And she didn’t have a clue about cholesterol or stuff like that. So you know, I just don’t know what you should believe.”

“My father, the first thing he did was put salt all over everything. Whether it was ham or hot dogs. He lived to be 94.”

“They are really on the average. You gotta go on the average. Ninety percent of the smokers are going to have problems in their life.”

Participants also expressed interest in and concern about Medicare coverage for preventive care.

Concern about Medicare coverage for preventive care

“Medicare doesn’t cover sometimes approved medicine.... The pap smear. It’s every other year. And the mammogram, they don’t want to pay that. And you take your physical, and that’s really preventative if you go once a year for your check up to make sure you’re all right. They won’t pay for that.”

Moderator: “How about preventative services, things like flu shots, medical check-ups?”

Participant: “I have a thought [about] ... this subject. Medicare does not pay for preventative services theoretically. I go for a check-up... I go annually. Medicare theoretically doesn’t pay for that. Now if there is anything that [Medicare] should pay for, it’s what I do to prevent myself from getting ill. They really should pay for that.”

Participant 1: “I was going to say, I think the best health insurance ... individuals our age can have... is to have an annual physical... I think the annual physical of people our age is an important thing, and not to wait for a good reason to go to a doctor, as some people do.

Participant 2: “Okay. But that’s not covered...Not an annual [physical].”

“Most of your health care organizations have that thing where if you want to do an annual physical over 65, you get this every year.”

A few participants mentioned additional information they would like to receive, including simple information about the risks associated with preventive practices such as risks for flu shots.

There may be a role for HCFA in helping beneficiaries understand and interpret competing claims about healthy habits. However, there does not seem to be a strong market for additional information on ways to stay healthy. It appears that HCFA has identified and is using effective methods for reminding beneficiaries about preventive care.

3.6 Other Information Needs

The focus group guide included explicit probes asking participants to report information they need about Medicare that they do not currently have access to. Although this was a difficult question for many participants, some groups reported wanting information about Medicare claims processes and procedures, including detailed information that would help them track their own claims and verify the services Medicare pays for.

Participants asked for a list of commonly needed resources so that when they need specific information, they could go to one place to find a contact.

Other information: Commonly used resource numbers

“It would be good if we had some sort of list that remains static; that doesn’t change, with certain things if you want to call... Where to contact this person, that person, or this agency, that agency. And that doesn’t change. ...[That would] be helpful in connection with trying to locate information.”

Some participants noted that they don’t necessarily lack information, but they often have trouble organizing or locating information they received earlier but have not needed until now. Participants also reported wanting to receive notices when there are changes in Medicare processes and procedures.

Other information: Assistance organizing information and tracking changes

“Well they have sent me so many books, it’s confusing. I don’t know what book is for what.”

“My experience has been... our secondary insurance... they send things all the time, even update the doctors and hospitals.... You save it all ... when they have dates on them you can eliminate by throwing .. out, but a lot of them aren’t [dated]... You forget what’s in the folder.”

I think that sometimes I find that there’s been a change made, but I’m not aware of the change.... It’s good to have one sheet of paper that says this is the change in the procedure... It’s in there. Perhaps... they do a new edition of the book that I’d have to look through again. It would be better if they had something specific [about changes]...”

“But today when you get a booklet, it’s a waste of time reading it, because it changes next year.”

Participant 1: “I think it would be a good—an extremely good idea for... the government to keep us posted, maybe not by the month, but yearly, on the different benefits we can take advantage of or look for with our Medicare coverage.”

Participant 2: “I think that would be wonderful... How do you know what the changes are, unless they point it out to you? And I just give up.”

Several groups discussed frustrations they had attempting to report or follow up suspected fraudulent charges made to Medicare. The Inventory Report also described general confusion about how to report suspicions of fraud. Focus group participants said they thought that staff they spoke with about their concerns were not sufficiently responsive. Participants reported encountering a general attitude that it is easier to pay fraudulent charges than to work through the procedures needed to determine whether services were actually provided and to eliminate fraudulent charges. Concerns with Medicare fraud seemed to be stronger among middle class and relatively educated focus group participants. Furthermore, as noted

above, concerns may be location specific and related to satisfaction with or confidence in the Medicare contractors in specific states.

Many participants expressed concerns about the financial future of the Medicare program.

Concerns about the future of Medicare

“My question is where does the money come from for Medicare? I know it’s tax money. Is it social security? When people pay into social security over their working years, isn’t that where the money is supposed to come from? It was supposed to be a large amount of money. Then I understood about the end of the 40’s, they began dipping into the fund for other purposes.... That’s my only question: Where is the money?”

“There’s lots of stuff about Medicare going out of business... What we hear on the radio that it’s out of business next year or five years.”

It will be important to identify more effective methods for coordinating and disseminating information about changes in Medicare coverage and procedures. Some beneficiaries are very concerned about Medicare fraud and waste, and they are under the impression that the Medicare program is not sufficiently attentive. When HCFA provides specific procedures for reporting potential fraud, it is important to respond to information that consumers provide.

4. SOURCES OF INFORMATION

This section describes beneficiaries' comments about and attitudes toward potential sources of information. Our analyses draw on two kinds of data: participants' descriptions of actual information-seeking experiences, and results from card-sorting exercises that participants used to rate alternative sources of information. The focus group protocol included two card-sorting exercises. For each exercise, participants sorted eight cards with the names of potential sources of information about Medicare. They were asked to sort the cards, first in order of how much information they had received about Medicare from each source, then in order by how much they trusted each source to give them accurate and complete information about Medicare. After each exercise, participants discussed their sorting orders and the reasons for their ratings.

We tabulated the card-sorting results for the general population groups to compute ratings of the amount of information from and the trust in each information source. The focus group participants are not a statistically representative sample of the Medicare population, so any quantitative analysis of the results cannot be generalized to the Medicare population as a whole. Nonetheless, the quantitative ratings provide a summary of focus group participants' attitudes toward the eight information sources. Exhibit 3 shows the mean, median, and modal rankings for the eight sources for the amount of information received and for trust. In all cases, lower numbers reflect better ratings. For example, the source assigned a rating of 1 for amount of information was first in terms of amount of information, and the source assigned a rating of 1 for trust was first in trustworthiness. Likewise, a source assigned a rating of 8 for amount of information was last in terms of amount of information, and a source assigned a rating of 8 for trust was last in trustworthiness.

Exhibit 3. Mean, Median, and Mode Ratings for Amount of Information Received About Medicare and Trust of Information Sources Based on Focus Group Card-Sort Exercises

| | Amount of Information | | | Trust | | |
|-------------------------------|-----------------------|--------|------|-------|--------|------|
| | Mean | Median | Mode | Mean | Median | Mode |
| Family and friends | 4.42 | 5 | 1 | 4.97 | 6 | 8 |
| Medicare contractors | 3.55 | 3 | 2 | 3.71 | 3 | 1,2 |
| Doctors, nurses, clinics | 4.10 | 4 | 3 | 3.79 | 3 | 3 |
| Radio, television, newspapers | 5.22 | 5 | 8 | 6.32 | 6 | 8 |
| HCFA | 4.98 | 5 | 7 | 4.09 | 4 | 1 |
| Supplemental insurance | 3.92 | 4 | 3 | 3.50 | 3 | 2 |
| People in the community | 5.69 | 6 | 8 | 5.62 | 6 | 7 |
| AARP and other seniors groups | 3.60 | 4 | 1 | 3.65 | 3 | 1 |

We will discuss results from Exhibit 3 in the following sections, covering each source in turn. In this section, we will describe some of the criteria participants said they used to make these ratings.

One obvious criterion for rating sources of information about Medicare is the knowledge that the source has on the subject—both the amount and accuracy of the information. Participants rated HCFA, Medicare contractors, and supplemental insurance companies high on knowledge. Timeliness is another important factor. Participants want information that is up-to-date, and most want specific information only when they need it (not before). AARP, because of its monthly magazine, got high ratings for timeliness. Also, sources that provided information in response to specific inquiries (Medicare carriers, supplemental insurance, some medical providers, some family and friends) were often rated highly.

The strength and length of the relationship between the beneficiary and the information source also seemed to be an important criterion. Participants described strong relationships with family, friends, and physicians. Some beneficiaries also reported a strong relationship with AARP, particularly beneficiaries who joined years before they were eligible for Medicare. A related criterion is how well the source understands the beneficiary and his or her situation. This understanding may be specific to the individual (family and friends, physicians), or it may be more generic (AARP).

Many focus group participants seemed to feel that the information needed to understand the Medicare program was overwhelming and complicated. They valued sources that were able to sort through all of it and present what was important, relevant, and accurate in a way that they could understand. Once again, AARP seemed to meet these criteria for many focus group participants. Several participants said that medical providers and family and friends also met these criteria.

4.1 Family or Friends

Across participants, the ratings for “family and friends” were bimodal. In other words, there were few neutral reactions to family and friends as sources of information. Participants who had older spouses, older friends and family members, or friends and family members in medical professions reported that they used their friends and family as frequent sources and that they trusted the information. People who reported relying on family and friends as frequent sources of information were more likely to be reactive rather than proactive about seeking information, and they also seemed intimidated by information from “official” sources. People who said they do not get Medicare information from family and friends generally agreed that their family and friends mean well, but they do not have the required experience with or knowledge of the Medicare program. Family and friends were most often cited in discussions as sources of information about supplemental insurance and choosing a doctor, as well as for general information about Medicare.

Friends and family who have related experience are good sources

“I think sometimes talking to friends and family, they do tip you off on things like that. If somebody has been through a certain kind of a surgery and they say different things, it tips you off ...”

“Yeah. I was just going to say it’s easier to talk to a friend who’s had an experience, then to try and dig through a phone book and find a number to call and you know, it stands to reason it would be easier.”

“We wouldn’t ask someone who hasn’t gone through something. That’s how I am at my adult center. I will ask the person who has already done this, or we had that, or I had to go through this. If I walked up to just anyone and said what can you tell me about your Medicare and they say I don’t know anything. Well, then they don’t know anything. You find the one that does.”

“I put family and friends at the top. I mean close to the top only from the standpoint I think, like you say, if someone has had an experience with that regard, you can depend upon that. I think you understand them more too, than if you go to the doctor or the insurance company. They start giving you all the this and that and 80 percent of this. Reasonable and customary of this and everything else. You’re just going around.”

“They are people our own age, you know, our friends. They keep up with some of the news that we might not have heard. So I trust them.”

Relatives in the medical profession are also useful sources

“I did that. Well my son-in-law deals with medical all the time so I always go by his advice. He has his own medical business.”

“I do because my son-in-law has a business and he’s involved in this situation, so anytime I have a problem, I just go and ask him.”

Family and friends mean well, but they don’t know about Medicare

“Just because a friend or family has said ‘I handled it this way ‘ doesn’t mean you can handle it that way. So I think they mean well but I just think you have to go about it yourself and dig out the information on your own.”

“It’s not that I don’t trust my family and friends, I don’t trust the information they may give me.”

“They try to do the best they can. . . . They just often don’t know the right answers.”

“You get a lot of information from family and friends, but then I find I have to check it out.”

Beneficiaries who rely on family and friends do so because of their special experiences or knowledge. Beneficiaries' friends and families seem to act as information sources that complement or support HCFA information efforts. We expect that friends and families will serve a stronger intermediary role for beneficiaries with special communication needs or functional limitations. In the latter cases, communication strategies directed to beneficiaries' families may be important for ensuring that information is delivered to the people who need it.

4.2 The Insurance Companies that Pay Claims for Medicare

There was considerable confusion about the difference between Medicare contractors, HCFA, and supplemental insurance companies. Many participants did not make clear distinctions as they ranked the information sources. Participants rated Medicare contractors high for the amount of information provided but lower for trustworthiness. A primary reason for the high rating for amount of information was that most beneficiaries receive EOMBs from the contractors. Across the focus groups, we observed diverse reactions to Medicare contractors as information resources, probably in part because beneficiaries' experiences with contractors differed across the focus group sites.

Participants reported that Medicare contractors are a good place to start when they have questions about Medicare. Participants generally agreed that Medicare contractors should be able to answer basic questions about Medicare benefits and coverage.

Medicare contractors are the place to start when looking for specific information

"I want to know the coverage for anything that I'm going to go through. I think that's the place to start. Once I find out what they are going to do then I go next to my doctor and find out whether he's going to accept assignment. And, he'll usually tell me what the hospital costs are going to be. Whether they will be all covered or I can expect a portion of that."

Participants who reported that they trust their Medicare contractors for Medicare information said their trust follows from the contractor's role: It is the contractor's business to pay Medicare claims. These participants said that contractor experience with beneficiaries' questions makes it likely that they will provide accurate information. Participants who said they do not trust their Medicare contractors as sources of accurate information cited delays, mistakes, lack of follow-through and general distrust as reasons.

Contractors trusted as valuable resource

“I had that. There were questions for which I called the insurance to get information about things that were puzzling me in regard not only to my mother, but myself. They gave me good information.”

“I think it’s informative. I keep my bills aside and when I get them I keep them. I staple them together and I know they are paid.”

“Primarily because we’ve dealt with them and they gave us the answers when there was a question before.”

Moderator: “So, from experience, you feel as though can trust them.”

Participant: “They happen to be the most reliable.”

Participant: “Because they deal with it all day long, and they should be very exact.”

“I guess you figure that they work with it every day, every hour of the day, that they’d have a pretty good idea—”

“They pay it and they tell you why they didn’t pay it and so forth. And if you have an ongoing illness you know that they are going to pay it continually.”

“They are in the business of paying claims therefore they should know what they are doing.”

“They are the ones who should have the information.”

Dissatisfaction with contractor, delays and errors

“However, I’ve found mistakes. When challenged, then they back down. So I haven’t got the same amount of trust in them.”

“As far as filling out the claims, a few times that I have had to call [the local contractor . That] ... has been very unsatisfactory for me. So I usually figure it out myself and don’t call them too much.”

“You know what’s bad is like the forms that come from the insurance company. Sometimes it’s like a year before that thing is paid and you really have to go back or search your memory for what you went in for. That kind of, I wish they would put on there what you went for. It would help you keep records so there isn’t a repeat of something.”

“You call, and you call, and you call, and you get—I don’t know whether they are answers or not, because you never hear anything half the time. Six months goes by and you’re calling back again to find out what happened to it.”

“I don’t think they watch it close enough....You really have to pursue ‘em to get to the bottom of your bills and your, to see what you really have to study and go over your stuff and not leave it up to the companies or you gotta question it. If you think they’re wrong, you gotta go after it. Because the line-up is that we’re gonna pay for it in the end if the government accepts the bill.”

Participant: “They are the ones you have to call. I mean..... ”

Participant: “Yes, that’s the only bad feature. You have to do that.”

Participant: “Trust, I wouldn’t say trust.”

“I can call my insurance company three different times with the same question and get a different opinion on the line. That’s why I feel I don’t trust them very much... Each time, it’s like the person is starting from square one and you’re starting from square one. And they pull up your record but they don’t seem to know what you’re talking about. So I don’t have too much trust in them.”

Participants' comments suggest that mixed reactions to information from Medicare contractors is due at least in part to variable carrier performance. Carrier performance is not a communication issue. However, the resulting general dissatisfaction and distrust might be addressed through communication efforts. For example, HCFA might provide a general resource for advocacy support or information. This information could affect how consumers feel about the services they receive from the Medicare system.

4.3 Doctors, Nurses, or Clinics

Participants reported that they rely on and trust information from doctors who are willing to take the time to talk with them. This may be related to the general preference for one-on-one, interactive resources documented in the Inventory Report. Participants' relationships with their providers were related to the likelihood they would rely on information from their doctors. Participants who had good relationships with their doctors trusted the information they got from them; participants who had weaker relationships with their providers were less trusting of information they got from their providers and said they relied more heavily on other sources. Participants also reported relying on providers as information sources because of their specialized knowledge and expertise.

Factors related to reliance on providers for information

Doctors who take the time to talk with patients are good sources of information

"Our doctor always sits down and goes through the whole bit with us."

"They usually tell me what is covered, what isn't covered and what you can expect and what you can't expect."

Beneficiaries who have strong relations with their providers rely on them for information

"It's the personal touch, for one thing, compared to a form that you receive that's sent or an article."

"They know you personally and they know your problems and they can give you the information."

"If you trust them with your life, why not with the paperwork?"

Provider knowledge and expertise

"You can't interpret like someone that's a little more knowledgeable and I have a lot of confidence in his judgment that he wouldn't just suggest something that was profitable to him. That he would be concerned about his patients."

"The fact that he's a doctor, he's much more believable ... He's gone through the medical school and he's got that knowledge, which the average person doesn't have. He's more believable."

Several participants said that knowing Medicare rules and Medicare procedures is not necessarily a doctor's job. Some participants reported that their providers' offices had other staff who could be valuable sources of information, but other participants noted that lack of knowledge in the providers' offices can be a problem in getting care that's covered and getting care paid for.

Providers themselves may know little about how Medicare works

"They are in the medical business. They are not in the paper business, and they don't know ... the rules and regulations really."

"That's not their job, that's not their function. I am going there to get help medically ... I ask them a question about Medicare and all they are interested in is getting their money."

Provider staff can be valuable sources of information

"I think most doctors have a person in their office that takes care of Medicare. They don't have to know, some other person takes care of it."

"I don't think if you get the person who gets the claims, they might know a little bit more about it. Even then I haven't had very good experience as far as that's concerned with anybody in the doctor's office."

Participant: "My doctor is strictly medicine. When it comes to paperwork, see the nurse."

Participant: "Most of them have someone who takes care of all the bills..."

Participant: "That's what I'm trying to say, the doctors don't always know. They're not aware."

Participant: "I think the nurses or receptionists have a pretty good idea what is covered by Medicare."

Participant: "Yes, but the doctor writes the prescriptions."

Participant: "You may want to ask the receptionist or the nurse if it is covered."

Participant: "I think the doctor should know. It's just my point, he should know, but they don't."

Participant: "Well, sometimes, like I said, sometimes something is covered, and six months later it's not covered. That's happened to me."

Providers and office staff can be a hurdle

"They doctor [will]... handle the medical aspects of it, but it really depends on what kind of staff he has out front."

"I don't know. You're absolutely right. But I don't know whether they've filed it. But at least back in the olden days when you were filing it yourself. You knew that you filed it and at least started it in the system. And you pay the doctor and he says he'll file it but I'm not always sure that he has done so. You wait a long time to get reimbursed."

For many beneficiaries, medical providers are an important source of information about Medicare. This is particularly true for beneficiaries with long relationships with particular providers. This also depends upon the willingness of the doctors or others in their offices to take the time to talk with beneficiaries. Medical providers are important partners with HCFA in getting information to beneficiaries. In some cases, HCFA may have limited ability to affect how beneficiaries react to information from their providers because information-seeking and trust are based on provider characteristics and on providers' relations with patients.

4.4 Radio, Television, and Newspapers

Participants rated the mass media low both in amount of information about Medicare and in trust. In discussing their distrust of mass media, participants mentioned perceived sensationalism of the media coverage, shallow treatment of news stories, and bias that some participants associated with commercially-provided information. Several participants mentioned political “scare tactics” used by the media, particularly in reporting about Medicare. (Most of the general population focus groups were held during the 1996 Presidential campaign or shortly after the election.)

Reasons for distrusting mass media

Superficial treatment

“They only give you sound bites. In order to really get any kind of information in depth, you either have to talk to someone or you have to send for booklets. It’s just too short. You really have to look at it, digest it and ask questions, but you can’t do that with TV.”

“They highlight a possible problem but they don’t go into it. There’s just not enough information. So, they’re saying this is a problem, it may affect you and you have to go out there and find out for yourself.”

“I find quite often they will give you a little blurb about something and you can interpret it any way that you want to. I don’t really put too much faith in them.”

Biased coverage

Participant 1: “They are very political. I think their scare tactics during this recent election were a big huge example of that. Saying that it would all be taken away. I don’t think either party intended to take it away. Maybe they wanted to make it more efficient or something, but I don’t think either party would have taken it away and yet, the media just over and over said that one party would take it away.”

Participant 2: “Yes, that’s the one thing they pounded on. Just over and over. They wanted you to vote for their party. Scare you away from the other.”

Participant 3: “Well, as they say, you tell a lie often enough, people will believe it. I just don’t trust that kind of reporting.”

“I don’t trust them because they’re too biased.”

Commercial interests

“We all do listen to the radio and certain programs on health in which a particular doctor has a show... He’s pushing some product... All you have to do is send them \$39.95 and we’ll send you this or that... That makes me very skeptical.”

Some participants felt differently, however. While acknowledging the shortcomings of radio and television, they said that discriminating viewers and listeners can pick up useful information, perhaps identifying topics of interest that can be pursued through other channels. Some participants identified particular radio and television programs that they felt were useful and that they trusted.

Discriminating consumers can learn a lot from mass media

“I think we pick up a lot of information without realizing it from newspapers and the TV. A lot of stuff that you hear on the news.”

“I like to get all the information I can and then draw my own conclusions. I don’t want to just rely on one source. They may or may not be right. This gives me an opportunity to form my own opinion.”

Moderator: “So there’s at least two drawbacks. They’re not accurate and they’re kind of selective in what they put out. Any pluses?”

Participant: “Well, that’s also a plus. At least they give us something.... They make you aware.... They let you know that they are on the verge of finding something ... There is a lot of good information they give on radio and television.”

“Well, I read a lot and listen a lot to the radio and the TV and my magazines and kind of use common sense. . . . You can’t just take one source and that’s going to give you everything. You’ve got to be diversified and take a little bit from each.”

Although participants expressed considerable skepticism about television, radio, and newspapers, with television faring the worst, these media reach most of the beneficiary population. Many beneficiaries might see and trust information presented thoroughly in an unbiased way, perhaps from non- commercial sources.

4.5 The Health Care Financing Administration

Besides being listed as a source of information for the card-sort exercises, HCFA was also discussed at the beginning of the focus group sessions, under the topic of “Who is Medicare?” Except for former Federal employees, virtually no one supplied HCFA’s name as the agency responsible for Medicare, and only one or two participants per group recognized the name once the moderator said it. In response to the question, “What is the name of the government agency that runs Medicare?” participants most often answered “Social Security,” or “Department of Health and Welfare.” The following discussion was typical.

Who is Medicare?

Moderator: “You’re all here because you’re enrolled in Medicare, which you know, is a health insurance plan. Almost everyone in the U.S. over 65 is on Medicare and some people who are under 65 and disabled are also on Medicare. When I say Medicare, who is that? Who is Medicare?”

Participant: “The government.”

Moderator: “What part of the government?”

Participant: “Social health department.”

Participant: “Social security.”

Moderator: “Does anyone know the name of the agency that runs Medicare?”

Participant: “It’s on the top of my envelope when they inform me of things, but I didn’t pay any attention.”

Participant: “Is it health and human services?”

Moderator: “That’s the department that it’s in.”

Participant: “The thing is, you have to understand about people in general... all they’re interested in is what they get and so forth. They’re not interested in names. They’re only interested in what comes to me.”

Moderator: “How about the Health Care Financing Administration? Anyone recognize that name?”

Participant: “I think that’s probably on the top of the envelopes that I get.”

Moderator: “I think it probably is and that’s the name of the government agency that runs Medicare. They are the people who have hired my company to do this work. Okay. That is under Health and Human Services, which used to be called, Health Education and Welfare.”

Participant: “Oh, it’s not called that anymore.”

Participant: “They’re pretty good. I get informed about anything that happens. If I am underpaid they inform me and if I’m overpaid they inform me.”

With these discussions as background, when the groups got to the card sort exercises, they were generally able to identify the HCFA card properly, although in a few cases there was still some confusion. In a few groups, a discussion of the Medicare Handbook also preceded the card sort. However, participants rated HCFA low in terms of the amount of Medicare information received. In general participants rated HCFA high in terms of trust. A few participants described negative experiences with or attitudes towards HCFA. However, a larger portion of participants said they trust information from HCFA because HCFA is the agency responsible for the Medicare program. While few participants said so directly, the underlying inference is that participants would be receptive to more information that explicitly identified the Medicare program as the source.

HCFA was rated high in trust

“Because I feel like that’s the organization that pays... they should have the best knowledge....”

“I think in this case you go to the professional. You go to the person who is actually in charge or the person who knows their facts, at least you assume that they do.”

HCFA should provide more information to beneficiaries

Moderator: “Well, since we’re talking particularly today about information. Would you like to get all your information about Medicare from the government.”

Participant: “Yes. Then I know it’s coming from the horse’s mouth.”

Participant: “Firsthand information.”

Participant: “Just think of all the money that would be saved.”

A few negative experiences with or attributed to HCFA

“The thing is sometimes you get someone... that just doesn’t know. They will give you the wrong answers. I’ve run across that so you have to get someone who really knows and can answer your question properly.”

“The Health Care Financing Administration the government agency that manages Medicare stuffs their paperwork with so much bureaucracy, repetition and saying the same thing many times in a different form in each way that by the time you finish even one page of their literature you have no idea of what you just finished reading.... I thumb through it and it’s trying to learn how to operate...how to drive a car by reading a book.”

Beneficiaries in general are grateful for their Medicare coverage and they are inclined to trust information from HCFA because it is responsible for the Medicare program. Trust is an important feature to beneficiaries. Therefore, communication strategies that build on this implicit trust and enhance HCFA’s visibility as an information source will be able to fill information gaps that cannot be met by other sources. The role of trust will be particularly strong in areas where beneficiaries recognize few other neutral sources^{3/4} for example, in selecting supplemental insurance.

4.6 Supplemental Insurance Companies, Medicaid and Medicare HMOs

As noted earlier, some participants were not clear on the distinctions between Medicare contractors and supplemental insurance companies. However, virtually all participants had some kind of supplemental coverage and were able to identify it during the discussions. Although we attempted to screen out HMO members and Medicaid recipients from focus group participation, a few participants belonged to these subpopulations. For those persons, “supplemental insurance companies” included Medicaid and/or HMO’s. Participants rated their supplemental insurance companies high both in amount of information

provided and in trust. Participants said they rated their supplemental insurance companies highly because they are responsive to requests for information, they answer beneficiaries' questions, and their answers are generally comprehensible.

Supplemental insurers provide needed information

“Recently I was having problems I call them up and they give me all the information I need. They answer everything. They make it simple and exact answers why things are done and why they should be done as to why they shouldn't be done.”

“There were some questions that came up in our reading this booklet. That's when we started to use the insurance company to get information. We got quite a bit....Things that were a little bit more involved, we would call them up.”

“My supplement, I trust them the most. They have been really good with us so I trust them the most.”

“My supplement gave me all the information about Medicare.”

“Yes. They will send me letters telling me they are not paying this or that. So, you go pay it yourself. AARP, my supplement, they send me letters telling me what they will pay or not pay, and that is it.”

Moderator: “What makes you trust that information?”

Participant: “Because I know what they are going to do.”

The high regard afforded supplemental insurers may be related to their relatively high visibility, compared with HCFA. These insurers appear to be important potential partners in improving information to beneficiaries because of their well-established channels and high level of trust.

4.7 Community Resources

The Inventory Report identified community resources as particularly important for beneficiaries with special communication needs. Our focus group results suggest that community groups are not particularly important resources for the general beneficiary population. Participants rated community sources low both in amount of information about Medicare and in trust. Most participants seem to have little experience with these sources, or at least didn't think of them as sources of information about Medicare. With further prompting, participants identified community resources they might use for information.

Community sources haven't been particularly helpful

Participant: "The only thing that's really, you know, might be appropriate, would probably be the library. And that would be a real problem to start looking up stuff."

Participant: "...[You'd have to] dig and so forth. I personally would not go to a library to check this out if I had a problem."

Moderator: "Have any of you gone to senior centers, other sources in the community to get information about health."

Participant: "Yes, I've been to some of the places and talked to some of the people there. I've gotten no more information than I have right now."

"How are we supposed to get that kind of information in church?"

"Never use them. Never ask questions and they never ask me. That's probably for the best."

With prompting, some good community sources

Participant: "The senior network is attached to [a local hospital]. Their programs are excellent."

Participant: "Medicare should put out a brochure to all the senior citizens, clubs and so forth and just have it on the desk there, where people can get this information if they wish..."

Participant: "All the major hospitals have these health programs, they are free. They conduct seminars all the time."

Participant: "They also send out material."

Participant: "Absolutely, all kinds of things."

Participant: "I thought a long time ago, why couldn't we use the public libraries. Have a computer in a public library where you go and request the latest information, the latest video ... that way you find out the doctors in the area that will take it or whatever. ...If I have some booklets at home, I don't know whether they are the latest or not. I have no way of knowing. They have sent me so many already."

"And I think most of us can get to the library. And I understand some of us can't get to the library. They are not mobile or have a car and there might be a problem there."

"I mean, we have our senior center and we ask them which is the best thing, whether you should have an HMO or not and they will tell you yes you should. And then you'll say which one is the best and according to what they know, they will tell you which one is the best and which is the cheapest and, you know. So we actually have it at the senior citizen's center, but they have a computer that they figure this all out on for you."

Although community groups may be a more important source of information for beneficiaries than was apparent in the focus groups, they are clearly partners who will reach fewer members of the beneficiary general population than supplemental insurers or AARP. Community sources have the advantage of easier in-person contact with beneficiaries and the potential for more in-depth and individualized information-sharing. Further, community sources may be more important information resources for some subgroups than for the general beneficiary population. The forthcoming subgroup report will explore this possibility.

4.8 Organizations Such as AARP and Magazines for Senior Citizens

Many focus group participants belonged to AARP, and most of these were very positive about AARP as a source of information. Although this category was intended to include other advocacy groups, virtually all discussion in this category was devoted to AARP. Participants rated senior organizations high in amount of information and in trust. Participants said they rated these organizations high because they were effective in looking out for the interests of senior citizens. Participants said that AARP's materials are easy to understand and very relevant to their needs. Many beneficiaries who belong to AARP joined well before they became eligible for Medicare, so they are used to receiving information from this resource.

AARP publications a leading source of information

“I think it’s an excellent publication. I think AARP magazine is excellent... I think... is more accurate than something you might read quickly in a newspaper or something like that.”

Participant: “I don’t think they have any profit motives. These insurance companies, I’m leery of them because I think they try to avoid paying anything they can avoid because it’s a bottom line profit for them. And I think the AARP have no ax to grind. I think they’re kind of telling it like it is. So I trust them a lot.”

Participant: “They are dedicated to the seniors.”

Participant: “The information is compact and it’s up to date and it’s excellent.”

“Because I probably get more information from that AARP publication than any place else and it’s right there and I can read it. And it’s updated.”

“I read their magazine. It is very informative for seniors. There’s everything in there that you need to know.”

“If you’re a member of AARP their monthly publication is excellent. It gives you the latest information on government action.”

“I belong to AARP and I get a lot of information from the periodicals that they send out. The magazine covers a lot of information that you are looking for.”

“Let me hop on that trust again. AARP is geared to my group. I assume that they have my interest at heart in terms of medical care. The newsletters and those kinds of things seem to be pointing right to my group again. I have to trust that. I think they are trying to do something. I assume whatever they report is for our benefit so I will listen to them and take their advice more than other sources.”

Participant: “It’s written in plain English, so the average person can understand it.”

Participant: “And that’s the crux of the whole thing. They may have all the information in that booklet [the Medicare Handbook], but it just doesn’t register.”

Moderator: “So you might say to Medicare you should look to these kinds of publications as examples of how to—”

Participant: “Instead of insurance terms.”

Participant: “They should write it appealing to the people, not, you know, stating boom, boom, boom, boom. It’s how they write it.”

In one group, one participant challenged the prevailing view of AARP, and got some others thinking. In another group, several participants expressed a less complimentary view of AARP, highlighting political and financial interests.

Questions about AARP's commercial and political interests

“Well again, thinking of AARP, it's sort of a political organization. I know that it does some good in certain areas, but... you sort of have to question, I think, why they are saying certain things. In fact, I think you should question just about everyone.”

“For me they have been very reliable and straight forward. I don't know, maybe that's not the case today. It's big business, very political.”

Participant: “They have various commissions on whatever they can sell. You can buy airline tickets, stocks and bonds. They're a sales organization as far as I'm concerned and have lost the true meaning of what it was intended to do.”

Participant: “Well, sometimes when they are a sales organization, they are also a political organization behind that. The sales part is part of the come on. Yet, it's a power structure. You said at one time they were all right. But, now you don't trust them as much.”

Participant: “The information that I get from them is true. Very precise.”

Participant: “I think they are very valuable as lobbyists to elderly people.”

Participant: “They can't very well put out a bunch of lies. They have to be getting it from someplace.”

“If there's a certain law coming up, they will interpret it and see if it's of benefit to senior citizens.”

“It used to be good, but they're—now they're political. You can't trust them anymore, because now they're backing certain candidates for office and things like that.”

“It is a big business.”

“And of course their literature they're putting out for a source of information, I feel it's biased because they're selling insurance themselves.”

Despite a few negative comments, the overwhelming view of AARP among focus group participants was that AARP provides useful information in understandable formats. AARP is obviously an important potential communication partner for HCFA, and their materials may serve as models for clarity. Participants' comments about senior organizations highlighted beneficiary awareness of sources' interests in providing information. Participants generally preferred information from neutral sources or sources that represent beneficiaries' interests.

4.9 Other Sources

Several participants mentioned other sources of information about Medicare during the course of the focus group discussions. Former employers were mentioned by a couple of participants, and others included lawyers and the National Association of Retired Federal Employees (NARFE). In the discussion of staying healthy, health clubs and nutritionists were also mentioned as sources of information.

Former employers, lawyers, and retiree associations as information sources

“You know what really should have been included, if you’re an ex-federal worker, you get a special retirement life magazine which is very pertinent to have here. And I get more information from that than from all this.”

“Why are lawyers not used as a source of information for this?... That they did this dealing, wheeling and dealing with Medicare.”

Moderator: “Does anyone else get information from former employers or any other employment related groups that’s not an insurance company.”

Participant: “We belong to the Motion Picture Health and Welfare. They are fabulous.”

Participant: “They sure are.”

Participant: “No, but NARFE has helped me in that. The letters to the editors are replete with all kinds of experiences. And if you read those, you very quickly catch up.”

Participant: “... they’re actual experiences. And you find yourself. Ah-hah. There I am.”

Current and former employers and retiree associations may be important information sources in some cases. These may be potential communication partners for HCFA, particularly for persons about to enroll. This topic will be addressed in forthcoming reports focusing on subgroups with special information needs.

5. INFORMATION MEDIA

This section describes beneficiaries' preferences for how they receive information. One participant quoted below summed up how a lot of beneficiaries seem to feel about getting information when they need it. Consistent with the Inventory Report findings, focus group participants consistently said they wanted interactive communication with people who understand and know the answers to their questions.

Summing up feelings about information media

“As far as I’m concerned as far as information from Medicare, there is nothing in the world like being able to get on the phone and get a one on one conversation with someone. You can explain what is the matter and they can give me the answer that I need to know without all the machines.”

5.1 Medicare Handbook

The groups varied in how many participants remembered receiving the Handbook. In some groups, most participants recognized it. In other groups, as few as half remembered receiving it. Most of the focus group participants who remembered receiving the Handbook said they glanced at it when it arrived and put it away for use as a general reference when they needed information. Those who had not received it were always glad to hear that we had extra copies to give away at the end of the groups.

Participants mentioned using the Handbook as a general Medicare reference to get information about their Medicare coverage. Few participants could identify specific things they learned by reading the Handbook. Only one participant in the 12 focus groups thought the Handbook was too glossy or expensive.

Reactions to the Medicare Handbook From People Who Have Used It

“No, it’s been read several times. The wife glances through it. She says there’s several things in there you should read. So I start reading some of it and it’s boring. So I still have not read the book. My wife read it and she understands it.”

Moderator: “Have you used it sort of as a reference guide or you use it just to kind of read through to familiarize yourself?”

Participant: “I would have to look at it to see, my memory is starting to go a little bit. Whatever it was that I was interested in at the time.”

“I was able to find what I needed in there. And I came away a little bit more knowledgeable.”

“It’s important if you’re in the hospital, but outside of that I have no use for the book.”

Moderator: “How often do you think you use it for information purposes?”

Participant: “Maybe 3 times.”

Participant: “I don’t even remember what it was I used it for to look at it.”

Moderator: “Do you remember any of the kinds of questions that you think you could answer with the information in this booklet.”

Participant: “A mammogram. I questioned that, whether I was eligible for a second one within a year. I’ve had Medicare since I’ve retired and I think I’ve used it twice. I’m really not a good example.”

A few participants had specific comments about how the Handbook could be improved. Participants suggested an index, a glossary, and a list of resource telephone numbers. One or two participants mentioned that they wanted a list of the procedure codes used on the EOMBs.

How the Medicare Handbook could be improved

“But it is totally generic. It has no glossary in it. It has no really useful information. . . . Our family received it just at the end of June. And I have read it, but once you read the generic information, that’s all it’s good for. It doesn’t help you when you’re dealing with your day-to-day and monthly bills and statements.”

“Maybe they could add it to next year’s Medicare handbook. Have another page of their resource phone numbers. Have a list so if you have a specific problem, at least you would know the first step to take... If you had it all on one page then maybe it would help you to make a start.”

When asked if the Handbook was understandable, most, but not all, participants who had read it were at least somewhat positive.

Whether the Medicare Handbook is understandable

“For the most part yes I did... There were some things that were a little bit involved and not quite clear. That’s what you’d call it in terms of understandability. Other than that it was pretty comprehensive and pretty clear for the most part.”

“One thing in communication with...[someone] who is not very knowledgeable. The communication is very simple, sound bite kind of things that you can quickly see and then the small print, someplace. It’s helpful to make it very simple at first and then the small print you can understand a little better.”

Participants seemed to recognize that the Handbook was designed to be used as a general reference. It might be enhanced through more layering in presentation and a few additional features, but it seems to function as a general guide, providing orientation to the Medicare program. A number of participants felt that the Handbook could present information more accessibly. Following results from the Inventory Report, the Handbook may be most useful as beneficiaries enroll in Medicare. Delivery might be timed to anticipate enrollment. It seems likely that strategic timing would help beneficiaries recognize the Handbook’s utility as a general resource.

5.2 Radio and Television

The focus group protocol included discussions of mass media both as a source of information and as vehicles for information. Participants’ comments suggested that it was difficult to talk about media channels independent of information content. Several participants mentioned concerns about the commercial interests that characterize many media resources. Participants said that the commercial interest often makes media information suspect. A few people found radio and television useful for health information, but most were distrustful of information provided by the media.

Usefulness of information from radio and television

“I think it depends on who is disseminating the information. Is it coming from somebody who represents a drug company?”

“I think it should require the sponsor to identify himself so you can use your own judgment.”

“I think it’s a good way to supplement the other information that we get, but maybe not that alone, but in addition to other things. ... if they report on some little finding that showed up, it may not be the whole research, but it at least clues you... So the next day you read more about it in the newspaper. And that gives you more clues.”

“I have one thing to add to that. I think most of the information we get is tainted... Unless it has, or is newsworthy, you’re not going to get the truth. You’re going to get what is made to be newsworthy... They are out there selling radio time, television time, they want to peak your interest. They give you half truths. They use quick words which lead us down one path. You have to be very, very careful. I don’t believe we get enough good information from the people responsible to disseminate it.”

Most participants rely on the news media for some information, so news media are effective channels for reaching many people. Participants were leery of information received from the media, however. They were concerned about commercial sponsors and sensationalism that can obscure a complete picture. Media are a good way to reach a large audience, but beneficiaries are likely to be suspicious of information provided through media channels.

5.3 Videos

A few participants, perhaps one or two in a group, had some experience with videos about health care topics. Several mentioned the Time Life series, but no one in any of the groups had bought or seen one of them. Some of the most positive comments about videos came from people who had seen or heard about tapes dealing with specific medical conditions or procedures. Several had seen this type of video in doctors’ offices. Participants mentioned videos in connection with other topics as well, including exercise and nutrition products.

Experiences with videos on particular conditions or procedures

“I know the doctor that I go to, if you’re going to have some sort of operation, they have a video there and I thought that was a great idea. It keeps some of the fear away. You already know what is going to happen and how it’s going to happen.”

“My doctor... he has the videos right in his office that are on his TV. The videos are played all the time. They are health care, all the information. Every time I come in I look to see if there’s something decent playing and it’s always something.”

“My insurance company. I just looked at one yesterday they sent me... You request... and they send you books... a couple of pamphlets and this video... on nutrition... you can get different ones for different things and it’s all free, which to me is amazing, in a way, you know.”

“We received one on prostate cancer which...was quite detailed and made him understand it... It came from a drug company... but it did have a lot of information on it and it ended up being the drug he ended up on anyway.”

Several participants reported having limited or no access to a VCR. Some participants who had used videos as resources mentioned relying on community resources for viewing them, including libraries, senior centers, and doctors’ offices. As with other media, the source of the information was an important factor in how participants reacted to video information. At least one participant was skeptical of a video because it was produced by a drug company.

Videos seem to be a good medium for conveying very specific information in a targeted way, as HCFA has already done with topics such as choosing a nursing home. As noted in the Inventory Report, videos will be particularly useful for topics where beneficiaries prefer or require more dynamic communication.

5.4 Newspapers and Magazines

A number of participants mentioned magazines. (Comments on “Modern Maturity” were covered in an earlier section on AARP.) Magazines were often mentioned as a source of information about staying healthy.

Magazines as a source for information about health

“Another source that I have found to be helpful to me is some of these medical newsletters that come out once a month... They have the latest reports from New England Medicine and so forth. You can read about—get updated on certain diseases and treatments for them.”

“Magazines are more complete on certain articles and certain problems or disease. I think they may delve into it more.”

Medical journals and periodicals on such topics as nutrition are an important information source for some beneficiaries, particularly those who are active information-seekers.

5.5 Notices in the Mail

Participants were ambivalent about receiving things in the mail. When asked how they wanted to get information, they most often mentioned the mail. When asked about what they already get in the mail, they were less positive. Participants said they receive a lot of “junk mail” that they do not review carefully.

Reactions to notices received in the mail

Participant: “I know what you’re saying. Here comes another piece of paper in the mail. Oh that’s from Medicare—”

Participant: “Throw it away.”

Participant: “This is from the police requesting another donation.”

Moderator: “How about notices that you get in the mail? Do you get notices about health in the mail?”

Participant: “A little bit.”

Participant: “I don’t read everything that comes. There’s so much of everything.”

“I have a problem with mail particularly the last quarter of the year. For a lot of us it is about 96 1/2 percent junk mail...”

Mailed materials are convenient because beneficiaries can go through them at their own pace. However, there are many mailed materials that beneficiaries do not review at all. If HCFA relies on mailings, they should be designed to be distinctive to enhance the likelihood that beneficiaries will notice and pay attention to them.

5.6 Computers and the Internet

Most discussions of computerized information sources focused on whether participants used computerized resources, the kinds of information they accessed with computerized resources, and the advantages and disadvantages they saw in using computerized resources. Because of particular interest at HCFA in computer-based dissemination of Medicare information, the focus group discussions went into considerable detail on participants' receptivity to obtaining information in this way and on potential barriers to the success of such a system. Only a minority of participants in each group said they had experience using computers, and overall only one or two participants overall had experience using the Internet. To introduce the discussion, or to further it as necessary, the moderator generally asked participants to presume that an easy-to-use, accessible system was in place.

Participants seemed to react to computerized information channels in two stages. First, participants focused on difficulties related to accessing and using computer resources. After describing concerns about access and usability, participants seemed better able to consider the more abstract potential value of computer information. Some participants seemed positive and open to computers, particularly because of the detail and interactive forms that are possible. Other participants were less open. Comments from the latter participants seemed to focus on cost, difficulties maintaining confidentiality, and difficulties ensuring accuracy.

Difficulties with computer access and use

Moderator: "Is that a way you would like to be able to get that information? To be able to go to the library or some public place?"

Participant: "There's a small problem."

Participant: "A lot of us in our age group are computer illiterate. So it would be difficult and..."

Participant: "Embarrassing."

Participant: "Embarrassing to go in and say to the librarian and say I need this information. And she'll say okay here's a tape, go over and use that machine over there."

Moderator: "Well time to fess up here. How many people would feel that way..."

Participant: "If I didn't know computers I probably would."

Participant: "I don't use the computer, but I don't mind asking anybody. As you get older you don't mind talking to people."

Participant: "That's the truth. It doesn't bother me one bit."

Participant: "It doesn't bother me."

Computers are a future resource

“That really is for people 20 years from now where everyone will be computer knowledgeable but today your senior citizens I would say 90 percent of them are not. And so it’s for a limited amount of people.”

Moderator: “Has anyone been on the Internet?”

Participant: “No, I haven’t but I have friends who have had serious illnesses and found some really good information there.”

Participant: “They can sometimes get more through there than the doctors and the hospitals.”

Participant: “It’s the wave of the future.”

Some participants were open to computer-based information

Moderator: “Suppose there was a place you could go, like a public library or whatever, and there was a—sitting in the public library is a computer terminal. And you could sit at the computer terminal and in a fairly easy fashion, have access to a lot of information about health, about health insurance, about doctors in your area.”

Participant: “I think it would be very interesting to have a computer at every library that you could do that.”

Participant: “You don’t even need that, in my experience. All you need is a fax machine, because some of this information is already prepared. So that when you dial the number you get the prepared layman’s language version. And you copy whatever number of pages.”

Participant: “And if you don’t have a fax machine at home, they have them. They’re very reasonably to use them.”

Moderator: “Suppose there were a very user friendly computer in a public place like a library that you could go to and you could get information. You could look up very specific information about particular conditions or about the Medicare Program and so on. Would that be a way that would be appealing to get information?”

Participant: “Yes it would but the only flaw in that how many of us at the Medicare age would be knowledgeable of using [it].”

Moderator: “That’s the point.”

Participant: “Now that would be my only concern. Most of the people that would need it wouldn’t be capable of using computers or wouldn’t be knowledgeable.”

Moderator: “Well there were several people here who have not used computers. Would you be game for something like this?”

Participant: “I think it would be great.”

Participant: “It’s a good possibility.”

Moderator: “Do you think this would be a way to get information about Medicare?”

Participant: “Sure.”

Participant: “As long as it’s easy.”

Participant: “Well, he said that it would be easy.”

Participant: “Well how easy is easy. You know. I have no idea, I don’t even turn mine on.”

Participant: “Well, we could learn a little bit....”

Participant: “It has to be simple.”

Moderator: “How do you feel about the information that you might get over the computer, over the Internet?”

Participant: “Fantastic.”

Participant: “I believe in it.”

Some participants could not be persuaded to try getting information from computers

- Moderator: "Now, assuming that a machine was accessible and that it was easy to use, is that a way you'd like to get information about Medicare."
- Participant: "Sure."
- Participant: "Not until I learn to use it."
- Participant: "Number one, you've got to have a way to get there. Number 2, what if you have a question that they don't have on that computer, then you have to run around trying to find someone to answer that question anyway."
- Participant: "I think part of the information could come that way and I know that the younger generation is really learning to use computers. It would be easy for them, but until we learn how."
- Participant: "Just watch the videos on TV instead of thousands of dollars for computers."
- Participant: "I don't believe that computer could get you answers to any questions that you had. It may get some, but not all."
- Moderator: "Suppose that you could go to one of these computers and check on the status of a claim that had been submitted to Medicare."
- Participant: "That's not a good idea for senior citizens."
- Participant: "Some people would like it."
- Participant: "It would be beneficial to people who are just going on to Medicare, but to us...."
- Participant: "What about an old, old, person."
- Participant: "We'd have to go to school and learn how to use them."

In several groups, one or more participants expressed concerns over confidentiality, and once the concern was expressed, others' enthusiasm for a computerized system dimmed considerably.

Beneficiary concerns about privacy

- "That'd be great. There's one other thing though. You know, how secure would that be. And that would be, to me, the biggest drawback."
- "Most of these computers you have to have your social security number or some identifying way of getting to all your critical information, you see."
- Participant: "But you know, when you sign your paper for doctors or that, you sign that if your insurance company needs this information, you're saying yes."
- Participant: "Sure, I don't mind..."
- Participant: "But, it's other people that I don't want in there."
- Participant: "I wouldn't let anyone know my personal problems. Supposing [someone] has this problem, I push his name and there I'll find out whatever I want. What's to stop this?"
- Participant: "Is this based on a number on our form or something."
- Participant: "It would be our social security number I would assume."
- Participant: "Yes, and only half the people in the world know that."

Concerns about the cost of a computer-based information system

“Once in a while you are going to have to have somebody else that Medicare is going to have to hire to stand by on this stuff and monitor it.”

Moderator: “Would that be a good way to get information about Medicare or about Health Care?”

Participant: “Yeah.”

Participant: “With minimal cost.”

Participant: “Don’t forget to get onto a net to be able to use that and that’s expensive as the devil.”

Participant: “I think that would be terrible. To go to the expense of trying to tell people of how Medicare works when they send out that booklet which explains everything that you need to know, is more than sufficient. Why on earth would the government want to spend more money on something as wasteful as computers.”

Participant: “Anyone sophisticated enough to have a computer can get the information on some other more down to earth fashion. Anything that goes into Medicare is usually in the newspaper.”

“There’s all sorts of communications methods. Don’t go into billions of dollars with this computer thing. I just get very angry at this.”

Concerns about maintenance and accuracy of a computer-based system

Moderator: “Would you trust the information you got from the computer?”

Participant: “I wouldn’t.”

Participant: “I trust practical. I’d stick to family or friends at that specific problem that I have. I wouldn’t trust the computer.”

Moderator: “Would there be another down side to using computers?”

Participant: “Inaccurate information fed into them could give you some...”

When you get right down to it, beneficiaries not enthusiastic about computers

Participant: “Let’s take a vote, does everybody like the computer?”

Participant: “I don’t know. When it goes that far where there are records and everything.”

Participant: “No, forget it.”

Participant: “It’s a nice play thing.”

“The more assistance you have like this, the fewer live people that you’re going to have in the future to sit down and talk to. I’d rather sit across the desk and talk to someone, someone who knows the system and has the computer there to look up things. I would feel much more comfortable.”

“I think this group here would use a computer only when it was necessary. I like talking to people myself.”

Although the focus groups generated some enthusiasm for computer-based information available from Medicare, the interest was mostly on the kinds of information and the ease of getting it rather than the medium. Beneficiaries in general were skeptical because of access, ease of use, cost, and privacy concerns. Future generations of Medicare beneficiaries will probably be receptive to and expecting computer-based information from HCFA. These focus group participants were generally not receptive. Although participants were generally resistant to computerized media, computers are likely to be an important component to effective communication strategies^{3/4} particularly as a medium for delivering information to partners who distribute information more directly to beneficiaries.

5.7 800 Numbers and Automated Telephone Menus

HCFA was also particularly interested in focus group participants' reactions to 800 numbers as a source of information. While participants had both good and bad things to say about 800 numbers as a source of information about Medicare, almost all were very vocal in their dislike of automated menus. Several participants described pretending that they had a rotary phone to avoid the menus.

Initial reactions to automated telephone menus

"The best thing is to stay on the line and pretend you don't have a push phone and wait till you get through."

Participant: "I hate it."

Participant: "I just hate those. It's so annoying."

Participant: "I want to talk to a human being."

"Well sometimes the whole listing that they give doesn't pertain to what you want anyway. Then you have to go through the whole thing and then you wait for an operator and if you're lucky, someone will come on."

"We were all brought up with the telephone. If you want to talk to someone you use the telephone. Now you talk to a machine, well, you don't talk the machine talks to you."

Participant: "I hate that."

Participant: "Very aggravating."

Participant: "If you get used to it, it may be all right. But, it's hard at first."

Participant: "I make believe I have a rotary phone. Then I talk to a person."

"There's no contact with anyone. The computer talks... the computer just keeps on rattling. Now, it will say press 1 if you want, you should press 1 now, you press that 1, what happens—that program goes all the way through then it stops and comes back and might start all over again...By the time you get through you forget what the heck you're talking about."

More initial reactions to automated telephone menus

Participant: “That’s the most frustrating experience I have ever gone through. You’re constantly punching numbers.”

Participant: “Then you don’t always get what you want.”

Participant: “They give you 8 choices and if you fall into one of those categories, then you jump to the next one...”

Participant: “You can’t talk to a human being.”

“I just think the operator should answer the phone and then connect you to the proper department. Like it was years ago and it will never happen again.”

“Medicare could set a precedent by getting us back and changing that and letting us talk to a human being or at least only one or two choices to get to a human being.”

“The category that is in your mind doesn’t necessarily always fit their list and you don’t know that until you get finished.”

Moderator: “So what do you think about these automated menus?”

Participant: “They’re a pain in the butt.”

Participant: “They’re headaches.”

“Although they may give you some information, I don’t think it’s worth the time and the effort.”

After the first four general population groups, the focus group discussion protocol was expanded to focus on automated menus in more detail. The intent was to go beyond initial reactions to explore participants’ tolerance for waiting, for sorting through options in a menu, and for reaching successive layers of options. When asked about how long was too long to wait, some participants observed that the answer depended on how much they wanted the information. The responses in general ranged from 2 minutes to 10 minutes, with most participants clustering around 5 minutes. When it came up in discussion, most participants reported that a system that informed the caller about how long they could expect to wait was very helpful. One or two participants mentioned systems that provided interesting information while the caller waited.

How long beneficiaries willing to wait to talk with a person

Moderator: “How long is too long to wait?”

Participant: “More than 5 minutes.”

Participant: “Five minutes tops.”

Participant: “I don’t mind 5 minutes, but if you’re waiting 20 minutes and then the dialtone comes on and you have to start over.”

Participant: “I have been on the phone sometimes 45 minutes.”

Moderator: “How long are you willing to wait?”

Participant: “That depends on how urgent your question is.”

Participant: “I’d say up to 5 minutes. 5-6 minutes.”

Moderator: “Let’s just say it’s not an emergency.”

Participant: “3-4 minutes.”

Moderator: “The earlier question, some of you said 5 minutes. Some of you said 3 to 4 minutes.”

Participant: “If it’s important enough I may be dialing that thing all day long.”

Knowing how long the wait will be

Moderator: “Who has had the experience of being on one of these calls and they tell you how long the wait is going to be?”

Participant: “I was just going to say that... There’s someone that I call and that is wonderful. They will tell you how many people are before you and approximately how long your call is going to be.”

Participant: “That’s wonderful.”

Participant: “You don’t mind waiting.”

Participant: “That’s a darn good idea.”

Participant: “But once you get through to social security. But doesn’t, there’s a record that says, your call will be answered in 7 minutes, or your call will be answered in 10 minutes.”

Participant: “Social security will tell you how many minutes, generally.”

Moderator: “Does that make you feel better?”

Participant: “Yes.”

Participant: “I like knowing how long I have to wait, yes.”

Participant: “Usually they get you in less than the time allotted.”

Some participants had no tolerance for punching in options from a menu. Some expressed anxiety about not getting it right, about forgetting the options after they had heard them, or about getting lost in a telephone menu and having to start over. Some were frustrated when the options didn’t seem to cover what they wanted. In general, participants who could tolerate selecting among options felt that three was about the right number.

Participants were also frustrated by repeated sets, or levels, of options. Some felt that any more than one set of options was too many; the plurality expressing an opinion seemed to think that two

levels were all right. Participants mentioned other specific frustrations with telephone menu systems, and some reported that they would rather do without information than go through automated menus to get it.

How many options on a menu are tolerable

Moderator: “Let’s say you do get a menu where you have a choice of options, how many options are too many?”

Participant: “Five.”

Participant: “I think four.”

Participant: “Three.”

Participant: “But after the third one, you’re already trying to remember what the first one said.”

Participant: “Then they tell you to push the button and you forget.”

Participant: “Three I can take, four is too much.”

Moderator: “How many choices do you think you should get at a single time?”

Participant: “Two.”

Participant: “Two, yeah right.”

How many levels of options

Moderator: “Okay, the last piece of this is you choose the option that you want and you get that and then another set of options. How many sets of options are too many?”

Participant: “Two or three.”

Participant: “Two.”

Participant: “Anything beyond two is too many.”

Participant: “It’s such a waste, what a waste.”

Other frustrations with automated telephone menus

Participant: “When they come on there, they shouldn’t talk too fast. I mean you don’t want to start all over again. Make sure we get that message. Speak clearly.”

Participant: “They end the message, too, you know... So you really don’t ask a question, they answer the question that they think you’re going to ask.”

While few beneficiaries had kind words for automated telephone menus, most seemed to accept that they were here to stay. An effective system for beneficiaries should have menu options that are clearly enunciated, clearly defined, and easy to use in classifying most information needs. Options should be limited, as should levels of options. Each level should have a “go back” option and should replay options, for people who don’t remember them all. If the system involves a wait, particularly for people who opt out of the menu, the system should inform the caller of the expected wait time.

6. SOME SIMILARITIES AND DIFFERENCES BETWEEN INVENTORY AND FOCUS GROUP RESULTS

The Inventory Report summarized the results from literature review activities and expert interviews. The focus group results reported here are based on structured but informal interviews with beneficiaries. Therefore, it is interesting and important to explore points of convergence and divergence across the two sets of results. This section highlights points of agreement and disagreement between results from inventory and focus group research activities.

6.1 Information Timing

The Inventory Report identified information timing as a particularly important feature of information interventions designed to provide information to Medicare beneficiaries. Interviewed experts reported that beneficiaries need information that addresses their immediate situations. Beneficiaries often have trouble understanding more general information that is not immediately relevant. These recommendations were supported by research results indicating that the general beneficiary population generally does not recall or understand their Medicare coverage. Beneficiaries with chronic needs understand their coverage more accurately and more thoroughly than beneficiaries from the general population. As frequent users of the Medicare system, information about coverage is both more important and more often relevant to beneficiaries with chronic needs.

The focus group results provide additional insight on information timing. Focus group participants reported two general information-seeking strategies: proactive information-seeking activities that involved collecting, reviewing and synthesizing information about Medicare, and reactive strategies that involved seeking specific information to address immediate problems or information needs. For example, some participants described proactive information searches they conducted to prepare themselves to select a supplemental insurance company. Other participants described searching proactively for information about treatments and assistance available for chronic conditions. In our focus group settings, reports of reactive searches were more frequent. For example, participants reported reactive searches for information about what they were expected to pay for their hospital bills and why specific claims were refused.

In some cases, it seemed that the proactive and reactive strategies reflected differences between beneficiaries with different problem-solving styles. In other cases, it seemed that the proactive and

reactive strategies reflected differences in the decisions beneficiaries faced, so that a particular beneficiary might be proactive in some situations and reactive in others. The Inventory Report identified layering as one effective strategy for communicating with Medicare beneficiaries. Individual and situation differences in the information-seeking strategies selected by beneficiaries may be one reason that layered approaches are effective. Proactive information seekers can choose their own level of detail, while reactive information seekers can focus on the information they need most immediately.

Inventory and focus group results confirm that timing is an important feature of effective communication efforts. Focus group results elaborate on earlier Inventory research findings by highlighting the importance of the match between individual beneficiary information preferences, the types of information needed, and the timing of the information provided.

6.2 Seamless Communication

The Inventory Report observed that Medicare beneficiaries react more positively when they are directly able to get information they seek. Relays, referrals, and gatekeepers are likely to frustrate beneficiaries who are seeking information. Focus group results are consistent, highlighting the importance of easy access and communication.

One-on-one communication is one way to enhance access, and the Inventory Report noted that beneficiaries react positively and are better able to use information that is delivered through one-on-one interactions. The Inventory Report suggested that beneficiaries may be particularly receptive to new technologies that mimic one-on-one interaction. The focus group results provide additional insight. Participants noted that noninteractive formats can be very effective for specific purposes, and participants were also sensitive to the costs associated with interactive formats.

For example, participants' initial comments about automated telephone answering systems were consistently negative. Several participants noted that when they call into automated systems, they prefer to use the rotary dial protocols and wait for a human operator to assist them. However, when moderators probed about features that could make automated systems easier or more convenient to use, several beneficiaries thought automated systems would be easier and more pleasant to use if callers received information about how long they would have to wait to get through to an operator. In addition, beneficiaries seemed to be more receptive to automated systems when fellow participants reminded them that human operators are expensive and that there are contexts where automated systems are quite convenient. Several beneficiaries mentioned that they actually like using automated telephone systems for

banking purposes because they can get the information they need without waiting to speak with a person. While the Inventory Report focused on the value of seamless information delivery, the focus group results clarify that Medicare beneficiaries are sensitive to considerations related to cost and context. The focus group results provide information that will be useful in helping Medicare beneficiaries understand and use the information resources available to them.

Beneficiaries with specific and immediate information needs generally preferred interactive communication formats. However, beneficiaries were sensitive to cost and they were responsive to suggestions that different formats suit different purposes. When cost is an important factor in decisions to use relatively inconvenient communication media, such as telephone automated response units (ARUs), beneficiaries are likely to be receptive and responsive to information about the trade-offs between cost and convenience. This information will be particularly important to beneficiary satisfaction when actual costs do not match beneficiaries' perceptions or expectations.

Beneficiaries said that they prefer printed materials for general information that they use proactively, but the key features for general information were: (1) the ability to review information at a self-selected pace and (2) the ability to return to the information as needed. It will be important to identify other media with these features since many beneficiaries complained about the volume of mailings they receive, and they are unlikely to recognize information gaps on their own or to know where to go to get general information once they know they need it.

6.3 Gaps in Information

The Inventory Report distinguished between two types of information gaps: gaps due to lack of information and gaps due to misunderstood information. This distinction was not evident in the focus group results because beneficiaries are not effective at distinguishing information they never received from information they received but did not understand. Focus group conversations were more useful for identifying types of information that beneficiaries need. The Inventory Report concluded that beneficiaries need (1) background information on the Medicare program and Medicare procedures; (2) information about ongoing changes in Medicare programs and procedures; and (3) information to help beneficiaries understand and make decisions between Medicare health care options by making trade-offs between plan coverage and plan costs. Focus group conversations revealed some beneficiaries who seemed to lack background information on Medicare coverage and procedures. It is difficult to identify subgroups of beneficiaries with specific needs based on the general population focus group results, but beneficiaries who relied on a spouse or partner to make health plan decisions often seemed to lack basic information about

how their health care is paid for. Our focus group results also suggest that beneficiaries with relatively low educational attainment might benefit from additional information on how Medicare works. Phase 2 focus groups with beneficiary subpopulations with special communication needs will address this question more directly.

In general, it seemed that focus group participants had difficulty identifying and speaking about the kinds of information they would like to have. A few beneficiaries said that it was hard for them to recognize and talk about what they don't know. There was at least one exception to this generalization. Several groups talked about wanting more information about changes in Medicare coverage and Medicare procedures. Many participants seemed to feel that such changes are frequent and significant. These groups discussed possible mechanisms for disseminating information about changes, including intermittent newsletters or booklets. They emphasized that the information should be simple and easy to understand, possibly using graphics or charts to highlight important changes and implications.

None of the groups spoke directly about wanting information to help them make trade-offs between health plan benefit levels and costs. At the same time, several individuals spoke about the relations between cost, quality and benefit levels. It seemed that the idea of making trade-offs between benefits and costs was familiar to beneficiaries, but they did not necessarily think of HCFA as a resource to help them make the trade-offs. Beneficiaries did speak of their concerns that in the near future they would be "forced" into managed care plans by the Medicare program. These concerns make it difficult for beneficiaries to view HCFA as an unbiased resource in selecting between health care options.

Focus group participants were particularly interested in new approaches to disseminating information about program changes. Given the value of this information to beneficiaries, program changes may be an area where beneficiaries will be willing to expend the effort needed to become comfortable with new communication technologies.

6.4 Effective Communication Strategies

Several communication strategies identified in the Inventory Report were echoed in comments from focus group participants. Focus group participants indicated clear preferences for simple presentation, with minimal use of jargon and technical or legalistic terminology. Participants' comments also agreed with the Inventory Report recommendation that information be available from a variety of sources, in a variety of forms. Increased breadth, for both sources and formats, would ensure that

beneficiaries with different preferences and information-seeking styles have access to the same cache of information.

6.5 Characteristics of Useful Information Sources

Participants mentioned several characteristics they thought were important in evaluating information from particular sources. Participants were generally aware of a source's motivation for supplying health-related information. For example, while a majority of participants said they trust information from AARP, a few participants noted that they interpret information from AARP carefully, because they recognize that AARP has business interests related to some of the health care information they provide. Likewise, participants mentioned taking care interpreting information from newspapers and television because these channels have interests in selling the information they provide. Reliability and recency were two additional characteristics that participants mentioned. For example, participants noted that it is relatively easy to distribute up-to-date information by newspapers and talk shows. Participants thought it would be more difficult to distribute changing information by videotapes or brochures. Some participants were dubious about efforts to distribute Medicare information over the Internet because it might be difficult to ensure accuracy. These characteristics—source motivation, reliability and currency—were themes that were mentioned in the Inventory Report and addressed more directly by focus group participants. Focus group participants also indicated that the strength and length of their relationships with information sources were important factors. AARP and medical providers were often cited as useful sources because of the familiarity and trust that had developed over a number of years.

7. SOME IMPORTANT FEATURES OF EFFECTIVE COMMUNICATION STRATEGIES

This section identifies a preliminary set of design features for effective communication strategies, based on the focus groups with general Medicare beneficiaries reported here. This list complements strategic considerations identified in the general beneficiary Inventory Report and is one source for a fuller set of recommendations that will be presented in the Synthesis Report. Following the structure developed in the Inventory Report, the communication design features are organized according to two dimensions: information content and how information should be presented.

7.1 Information Content

The focus group results presented here are in agreement with Inventory Report findings that beneficiaries want and/or need basic information about the Medicare program and how it works, timely information about changes in the Medicare program, and additional information to help them select from the relatively complex sets of insurance and health care options available to them. Based on focus group participants' comments, we have identified six additional information domains where HCFA is likely to be recognized as a particularly trusted or as a particularly knowledgeable source.

- 1. Information about HCFA.** Beneficiaries may not know HCFA by name, but they invest considerable trust in the agency because of its role administering the Medicare program. HCFA communications should be developed to identify and advertise the agency and its role. If the agency's name is more widely known, then HCFA communications can build on beneficiary trust. Information from HCFA would be more immediately recognized as objective, particularly in comparison with information from organizations with vested commercial interests. Also, it may be helpful to begin relationships with persons about to enroll more in advance of their eligibility dates to develop name recognition and trust.
- 2. How to use HCFA as a source of information.** Attitudes toward and satisfaction with information sources are related to consumer expectations. Focus group participants described the frustration they felt trying to get answers to specific questions about their Medicare benefits and coverage. Information about how to use Medicare information resources and which resources to use for which purposes should be designed to help beneficiaries avoid these frustrations. Information might be provided directly to beneficiaries, perhaps in the form of a list of resources, addresses, and telephone numbers. The same information about how to use HCFA information resources should be used to train telephone operators, counselors and other information partners who interact directly with beneficiaries.

3. **Anticipating difficulties.** Information designed to help beneficiaries anticipate and avoid common sources of confusion is another method for enhancing beneficiary satisfaction. Information about common problems could also be used proactively to identify information that beneficiaries are likely to need before small difficulties become large problems.
4. **Assistance resolving conflicting claims.** Focus group participants felt they receive conflicting or contradictory information about Medicare benefits, Medicare coverage, and Medicare claims processes. They seemed to feel caught in the middle of conflicts among health care providers, insurance companies and the Medicare program. The apparent contradictions may stem from misunderstandings or incomplete understandings about how Medicare works. As noted in the Inventory Report, it will be difficult for HCFA to overcome these contradictions by explaining the program in all its complexity. However, HCFA might go a long way toward alleviating the frustration and confusion by providing a problem-solving resource that works with beneficiaries to help them sort through and resolve conflicts and contradictions. Given the complexity of the system, and the generally reactive nature of situation-specific information-seeking, interactive communication formats, especially live telephone operators, may be the best method for providing this kind of problem-solving information. In this context, it is important to note that beneficiaries said they trust sources who they perceive as advocates. This is a domain where HCFA can build on its already high esteem by advocating for beneficiaries to ensure they have access to their benefits.
5. **Assistance in decision making.** Medicare beneficiaries are aware that they have complicated decisions to make about the health care options available to them. For example, beneficiaries mentioned difficulties finding health care providers they trust, selecting a supplementary insurance plan, and evaluating competing claims made by different Medicare HMOs. Beneficiaries do not look to HCFA to provide detailed information about individual providers or insurance companies. They generally rely on closer and more personal resources for this kind of information. However, there is a general unaddressed need for assistance in understanding and structuring complex decisions about health care options—especially about supplemental insurance and Medicare HMOs. Beneficiaries recognize that HCFA has particular expertise in the domain of health care options. It is likely that beneficiaries will be receptive to assistance from HCFA (or partnerships involving HCFA) in understanding and evaluating complex alternatives.
6. **Reporting Medicare fraud.** Beneficiaries expressed considerable concern about Medicare fraud, and they were particularly frustrated that the people to whom they reported their concerns were not sufficiently responsive to the information. Beneficiaries asked for clear information about how to report fraud and about HCFA's procedures for investigating and following up suspicious claims. Also, beneficiaries said they would like investigators to provide followup information about how their particular situations were resolved. Follow-up about particular situations might be less important if beneficiaries were confident that charges of fraud were treated seriously and followed conscientiously.

In selecting domains and communication strategies, it is important to use HCFA's cachet carefully. Focus group participants were wary of government agencies getting involved in domains where government does not have an established role. For example, focus group participants were not interested in getting information from HCFA about ways to stay healthy. They rely on health care providers and other sources for that kind of information. However, HCFA may have an important role to play as facilitator, helping beneficiaries to determine when it is appropriate to seek information from HCFA, and where to go when other types of information are when it is needed. Furthermore, by selecting effective communication strategies, HCFA will have the opportunity to maintain and build upon its own credibility by doing a particularly good job of providing the information that beneficiaries expect and need most from HCFA.

7.2 Information Presentation

The Inventory Report identified several important presentation features that were echoed by focus group participants. Participants said they prefer information that is presented simply, with minimal use of jargon or technical terminology. Participants said they prefer sources that distill complex information and present the key pieces of information that beneficiaries need to know. The Inventory Report recommended layered presentation formats that help beneficiaries identify the level of detail appropriate for their needs and preferences. Focus group results confirm the utility of layered formats. There were considerable differences across participants in preferred levels of involvement in claims processes and preferred levels of detail about claims outcomes. Effective layering will give beneficiaries the opportunity to choose a level of detail that meets their individual felt needs.

The Inventory Report also documented the importance of presenting information in a variety of formats and media so that beneficiaries with different information seeking habits and different information processing habits will be able to find important information in forms that make sense to them. Focus group participants suggested a variety of formats for presenting Medicare information, including glossaries of Medicare terms, diagrams of Medicare components and processes, charts comparing Medicare options, separate sets of telephone numbers for information and assistance, meetings and seminars for presenting complicated information, and detailed examples to illustrate how Medicare procedures work and how health care components work together to provide care for beneficiaries. Beneficiaries also reported relying on AARP magazines for detailed information. AARP materials provide useful models for clear presentation formats. Under information partnerships, existing AARP materials may serve as venues for some Medicare communications.

When asked, participants said they generally prefer written information materials over materials provided through other media. They mentioned two features of written materials that make them especially useful. First, beneficiaries can work through printed materials at their own pace. Second, beneficiaries can use written materials as references, returning to them when necessary. At the same time, participants complained about the amount of mailings they receive, and their comments suggest that they throw out a lot of mailings they receive without really looking at them. Therefore, it is important to capitalize on alternative methods for delivering printed information materials. In addition, beneficiaries might be able to use print materials more effectively when they are designed and presented in formats that help beneficiaries organize and store them for future reference. It will also be important to identify alternative information media that have the positive features associated with printed mailings without the drawbacks. The Internet might be exploited this way, if it is possible to overcome difficulties related to access and general lack of computer knowledge.

Timing was another communication feature that the Inventory Report identified as important. The Inventory Report focused on the importance of information timing in answering situation-specific and more general information needs. Comments from focus group participants highlighted another important aspect of information timing. Participants noted that they have learned a lot about the Medicare program and about their benefits through their experiences with the program. Based on experience, beneficiaries learn which questions to ask before receiving care and where to turn for assistance when they have problems or questions. Based on these observations, HCFA can anticipate that beneficiaries will benefit from intensive, probably interactive communications as they begin to use the program or as they begin to make use of new types of services (e.g., home care, hospital care, or nursing home care). If early experiences and early information interventions provide effective learning experiences, then less intensive communications will be necessary to maintain familiarity with the program and to update information about benefits.

Participants were very interested getting access to regular information about Medicare changes. They preferred simple but frequent updates, providing concrete information about program features and benefits that have not changed in addition to information about things that have changed. While it would be possible to provide relatively general information that would be suitable for all beneficiaries, focus group participants preferred information that is tailored to their particular circumstances. Therefore, partnerships with Medicare contractors, supplemental insurance providers, employers and Medicare HMOs may be a more effective method for supplying information about changes in beneficiaries' benefits.

We have noted that focus group participants manifested different information-seeking strategies. These differences seemed to reflect both individual differences in decision-making styles and situation-specific differences in the kinds of information needed. Some participants were proactive information seekers, interested in gathering information before they would need to use it. Other individuals were reactive information seekers, waiting to look for information until they had a specific need for it. Individuals' preferred information-seeking strategies are constrained by and molded to the situations they are in. For example, most participants were at least a little proactive in seeking information about supplemental insurance, while few were proactive in seeking information about hospitalization procedures and costs. These observations are consistent with findings documented in the Inventory Report, and they suggest that effective communication strategies should be responsive both to individual differences in decision-making styles and to situation-specific factors. Responding to beneficiaries' information needs and preferences will require flexible materials that can be delivered either proactively or reactively, as needed. Furthermore, reactive information-seekers do not want to receive, and may be unable to use, information that is delivered before they need it. Effective implementation will require developing and tracking diagnostic indicators about individual beneficiaries' decision styles, probably based on past requests for information. Thus, it may be necessary to build upon systems used to disseminate information about the Medicare program so that the systems can also collect information about beneficiaries' information-seeking styles.

Finally, we note that many participants found the focus groups themselves useful sources of information. Proactive information-seekers among the participants were very pleased to share what they had learned. While formal focus groups are very inefficient as dissemination vehicles, other HCFA-initiated outreach efforts that bring beneficiaries together to talk about the Medicare program can serve both as a means to disseminate information and as a continuing vehicle for HCFA to obtain feedback on its communication strategies.

REFERENCES

- Bureau of the Census (1996). Statistical Abstract of the United States. Washington, DC: Government Printing Office.
- HCFA (1995). Information Needs for Consumer Choice: Focus Group Report.
- Patton, M.Q. (1990). Qualitative Evaluation and Research Methods. Newbury Park, CA: Sage.
- Taylor, S.J. & Broden, R. (1984). Introduction to Qualitative Research: The Search for Meanings. NY: Wiley.

APPENDIX A

FOCUS GROUP

MODERATOR'S GUIDE

HCFA On-line: Market Research for Medicare Beneficiaries
Focus Group Protocol
November 25, 1996

I. Introduction [5 minutes]

Good afternoon (evening) and welcome to our session. My name is _____. I work for Westat, a research firm located just outside of Washington, DC. As you may have been told, the Health Care Financing Administration (HCFA), the Federal agency in charge of Medicare, has hired us to come and speak to folks like yourselves about the information you need about the Medicare program and more generally about the information you need about your health and health care.

The technique I am using today is called a focus group. We are going to focus our discussions on information about Medicare and information about your health. Before we begin, let me remind you of some ground rules.

We will be on a first name basis only. *[MAKE SURE ALL NAME CARDS FACE TOWARD YOU AND THAT NONE ARE OBSTRUCTED]*

There are no right or wrong answers in this room--just your opinions. I need to hear what each of you think about the topics we are going to discuss, so please speak up. Feel free to disagree, but please wait your turn to speak. You may refer to each other, but please use only the first names on the name cards. Only one person should talk at time.

Behind me is a one-way mirror. There is a colleague from Westat [and some representatives from Medicare] who will be watching. They want to learn as much as possible from your opinions. We are also tape recording the session because we don't want to miss any of your comments.

This is a research project. There will be a report written about what we have learned from you and from other people we are talking with both in this area and in other parts of the country. Some of your words may be part of our report; however, no names will be used in the report, and Medicare won't be given any names or information about you. What you say will have no effect on your Medicare benefits, so please be frank. What you say will help Medicare be more responsive to the information needs of beneficiaries.

Our session will last about an hour and a half to two hours.

Are there any questions before we begin? Just a few logistics. The restroom facilities are located _____. There are no scheduled breaks since we have so much to discuss. However, please feel free to excuse yourself if necessary.

I've passed out an Information Sheet. Let's take a minute or two and fill out the front of that sheet. We'll get to the back in just a few minutes.

Let's start our discussion by going around the table. Introduce yourself and tell us what got you interested in this discussion about health and health care. I'll start.

II. Information about the Medicare program

A. Who is “Medicare”? [10 minutes maximum]

You’re all here because you are enrolled in Medicare, which is a health insurance plan for people over 65 and for some people under 65 who are disabled. Almost everybody in the United States over 65 is on Medicare. My first question for you is, Who do you think of when I say “Medicare”?

Probe if needed: Is it a government agency or an insurance company or what?

Encourage some discussion, but limit this section.

If no one mentions HCFA, probe: Do you know who runs the Medicare program?

If no one mentions HCFA still: Have you heard of the Health Care Financing Administration?

If no one knows who HCFA is, say: The Health Care Financing Administration is the Federal government agency that manages the Medicare program. They are part of the Department of Health and Human Services. Do you remember seeing the name on any letters or pamphlets from Medicare or on the Medicare Handbook?

B. Recent experiences getting information about Medicare [20 minutes]

I'd like you to think about a time recently that you tried to get information about the Medicare program -- any kind of information at all. What information have you tried to get recently?

OPTIONAL: On a flip chart or white board with two columns, write the information items desired as they are reported. As an information item is reported, ask if others have tried to get the same information.

After all information items recorded: From whom did you try to get this information?

Record sources on flip chart, match up with information items. As a source is mentioned, ask if others have tried to get information from that source.

After getting sources, follow up on each source/item reported (or as many as time allows).

What form was the information in? (i.e., booklet, letter, Q&A, audio, video, on-line) Did you understand the information? Was it accurate and complete? Was it what you needed?

If anyone mentions "Medicare" as a source of information, probe:

Who do you mean when you say "Medicare" -- what was the name of the organization you called? [Did you call the government agency that manages the program, an insurance company that pays the claims, or whom?]

C. Card sort -- where received information about Medicare [20 minutes]

Next, I'd like you to think about all of the sources from which you have received information about the Medicare program. On the table in front of you are several sets of cards. I'd like you to take stack number 1 now. Each of the cards in Stack 1 has one possible source of Medicare information. Let me read the sources:

- A. your family or friends;
- B. the insurance companies that pay claims for Medicare;
- C. your doctors, nurses, or clinics;
- D. radio, television, and newspapers;
- E. the Health Care Financing Administration (the Federal government agency that manages Medicare);
- F. your supplemental insurance company; [Medicaid/your HMO]
- G. people in your community, such as at senior centers, churches, libraries, etc.;
- H. organizations such as AARP and magazines for senior citizens.
[not for disabled group]

What I'd like you to do is to sort the cards in order by how much information about Medicare you have received from each source. That is, you would put the card for the source from which you have received the most information on top, the one for the next most information under that, and so on, with the source from which you have received the least information on the bottom.

Are there any questions?

When everyone has finished, ask them to record in Column II of the Information Sheet the letter of each card next to the number of its order in the stack -- the top card is number 1, etc.

What did you have as the top card? *Encourage discussion of choices for top one or two information sources.*

Throughout this exercise, as participants mention Medicare carriers, HCFA, or supplemental insurers, probe to determine whether they are clear on which one they are talking about

After discussion of sources providing the most information: Are these sources you've selected at the top of your list particularly convenient or inconvenient ways for you to get information?

And which card did you have on the bottom? *Encourage discussion of choices for bottom one or two information sources.*

After discussion of sources providing the least information: Are these sources you've selected at the bottom of your list particularly convenient or inconvenient ways for you to get information?

Are there any information sources that you use that we didn't list on one of the cards? Are there any sources you would *like* to use or to use more?

| |
|--|
| <p><i>If more than 45 minutes into session, skip the next card sort.</i></p> |
|--|

Next, I'd like you to sort the same cards again -- this time, by how much you trust the source to give you accurate, complete, and understandable information about Medicare. The top card would be the source you trust the most for information about Medicare, the bottom the source you trust the least.

Ask participants to record this card order in Column III on the Information Sheet

Now which card was on top? *Encourage discussion of most accurate and understandable sources. Probe as needed:* Why do you trust {SOURCE} to for information about Medicare?

And which card was on the bottom? *Encourage discussion of least accurate and understandable sources. Probe as needed:* Why don't you trust {SOURCE} to be accurate and understandable?

D. Medicare Handbook [5 minutes]

Hold up copy of Medicare Handbook.

Do you recognize this? How many do? _____

Do you have one at home? How many do? _____

Do you ever use it? How many do? _____

What kind of information do you look up in it?

| |
|--|
| <i>If more than one hour has passed, skip the following:</i> |
|--|

Is it clear? Does it have information you need? What's missing or not clear?
Encourage discussion of specific uses, if any mentioned.

E. Information about Medicare Still Needed [10 minutes]

We've talked a lot about the information you *get* about the Medicare program. What about information you *don't* get? Is there information you need but don't get about the Medicare program? *Probe for details of information needs, why information is needed.*

What about information you get but don't understand? Is there anything about the Medicare program that you don't understand and would like clearer information about? *Probe for details of needs, why information needed.*

Where or how would you like to get this information? *Follow up with each need mentioned.*

III. Information about Supplemental Insurance [10 minutes]

People enrolled in Medicare often have other health insurance as well. Some people have what are called supplemental or “Medigap” policies that pay the deductibles, copayments, and for some services Medicare doesn’t cover. Other people have supplemental insurance that covers just long term care, things like stays in a nursing home. Still other people have supplementary coverage through the Medicaid program.

How many of you have supplementary health insurance that pays for some of the things Medicare doesn’t cover?

How many of you had a *choice* of different plans for your supplementary coverage?

Do you feel as though you had enough information about supplementary insurance to make the choice? What other information would you like to have to make this kind of a choice? How would you like to get this information? (In what form and from whom?)

IV. General Health Information Needs

I'd like to change the subject a little at this point. We've been talking about the information you need about the Medicare program and other health insurance and how you get that information. The agency that runs Medicare would like your advice about other health-related information you need and how they might help you get that information. There are many different areas that might be included here -- I'd like to take a few of them one at a time.

A. Information about Choosing a Doctor [10 minutes]

First, how about choosing a doctor?

Do you feel like you get the information you need to help you choose a primary care or "regular" doctor?

If "Yes": What information do you get? From whom? How is it presented? Do you trust it?

If "No": What information would you like to have? How would you like to get that information?

Do you feel like you get the information you need to help you choose a specialist?

If "Yes": What information do you get? From whom? How is it presented? Do you trust it?

If "No": What information would you like to have? How would you like to get that information?

B. Information about Staying Healthy [10 minutes]

Next, what about information about ways to stay healthy, such as what foods you should eat and what kind of exercise you should get.

Do you feel like you get the information you need to help stay healthy?

If “Yes”: What information do you get? From whom? How is it presented? Do you trust the information?

If “No”: What information would you like to have? How would you like to get the information?

P If preventive services not mentioned: Do you feel like you get the information you need about preventive medical care, like check-ups, mammography, and flu shots?

If “Yes”: What information do you get? From whom? How is it presented? Do you trust the information?

If “No”: What information would you like to have? How would you like to get the information?

D. Other Information Needs [5 minutes]

We've talked about getting information about the Medicare program, about choosing a doctor, and about information on staying healthy. These are only some areas dealing with your health and health care in which you might need information. We don't have time to talk in detail about other areas, but I'd like to give you a chance to mention any that you think are important. Remember, we're asking for your advice to the Medicare program about the information you need about health and health care.

In what other areas do you feel that you need information? *Continue to elicit suggestions, probing for clarity, but do not get into extended discussion about any particular area.*

E. Sources of Information [15 minutes]

We've talked about many different sources of information about your health. I'd like to ask you briefly about a series of sources, and get an idea of what you think is good about the information you get from that source, and what is bad about it. For example, you might like the way information is presented, you might trust one source over another, you might find the some information more suited to your own needs, you might find some information too hard to understand.

For each source that has not been thoroughly discussed previously, probe: What's good about the information you get from [SOURCE]? What's not so good about it?

Sources:

- your family and friends
- your doctors or nurses
- your health insurance plan
- newspapers, radio, and television
- AARP or other senior citizens' groups
- your local library
- senior centers or other community sources
- the Medicare program
- the Surgeon General
- *other sources mentioned in the discussion*

F. Information Media [15 minutes]

Finally, I'd like to talk a bit about the different media through which you get information about your health and health care. By "media," I mean written material, TV or video, telephone conversations, face-to-face conversations, and so on. Again, I'd like you to say a bit about what's good and what's not so good about each medium, or way of getting information.

For each medium, probe: What's good about getting health information this way? What's not so good about it? Try to focus discussion on medium, rather than source or content.

Media:

- radio and television
- videos [Has anyone obtained health information from videos, either at home or at a library or community center? What kind of information was it?]
- newspapers and magazines
- notices you get in the mail

800 numbers/automated phone menus

What about 800 numbers? How many of you have tried to get information about Medicare or some other health topic by calling an 800 number?

And how many of you have reached a recorded message asking if you have a touch tone phone when you called an 800 number?

What do you do when you reach that kind of message, where you might have to enter some numbers to get to where you want to go?

If people express anger or frustration about automated phone menus, probe for the reason for the anger/frustration.

Suppose you didn't have to do anything other than wait for someone to come on the line. How is that, compared with having to enter numbers?

How long would you be willing to wait on such a call before you got impatient -- 10 seconds, 30 seconds, a minute, three minutes, five minutes?

When you have to enter a number from a list the machine reads to you, does the length of the list make a difference to you? How many options do you think is too many (two, three, four, five . . .)?

How about when you enter one number, and then get to another menu that asks you to enter another number? Is that a problem? How many selections are you willing to make to get what you want (one, two, three, four, five . . .)?

Computers/Internet

One more way to get health information is by using a computer.

How many of you use computers?

Do any of you use the Internet? Do you get health information from the Internet?

HCFA is thinking about helping you get access to computers in public places such as libraries, senior centers, and Medicare offices.

What would you think about getting (INSERT INFORMATION TYPE) through these computers? Do you think there are any drawbacks to getting this kind of information by computer?

- (information about how Medicare works)
- information about supplemental insurance plans
- (information about managed care plans)
- general instructions on how to file Medicare claims
- general information about what's covered and what Medicare pays
- information about your own personal claims

What would you want to be able to find out about your claims? (Would you want to get basic information about who has filed claims for your care, when the claim was filed, and whether it was paid? Would you want descriptions of services received? Would you want information about the codes and identification numbers on the claim forms?)

Do you think a computer is a good way to get this kind of information? What makes you say that? Do you think there are drawbacks to getting this kind of information by computer? (Do you think people would feel comfortable using a computer to get access to their personal Medicare records?)

Summary on Sources

Now that we've talked about all these different ways of getting information about Medicare and other health-related topics, where would you most like to be able to get health information?

IV. Wrap-up [2 minutes]

Thank you very much for your time. This has been very helpful.

Describe procedures for getting paid, how to leave, any other logistical details.

We have put out some information that you might find helpful. *Say where it is.* Feel free to take one of any of the materials you want. Please don't take more than one, though, because we only brought a limited supply.

Again, thanks for your help.

Table has Medicare Handbook, other HCFA pubs; 15 copies each. Count and record how many are taken of each pub.

Focus Group Information Sheet

1. Are you male or female?

- ☐ Male
- ☐ Female

2. How old are you?

- ☐ under 65
- ☐ 65-69
- ☐ 70-74
- ☐ 75-79
- ☐ 80-84
- ☐ 85 or older

3. Do you take care of your own paperwork for Medicare, or does someone else, like your husband or wife or a child, do it for you?

- ☐ Do it myself
- ☐ Someone else does it

4. Are you of Hispanic origin (e.g., Cuban, Mexican, Puerto Rican, Latino)?

- ☐ Yes
- ☐ No

5. What is your race?

- ☐ White
- ☐ Black or African-American
- ☐ Asian or Pacific Islander
- ☐ American Indian or Alaska Native
- ☐ Other

6. How far did you get in school?

- ☐ 6th grade or less
- ☐ 7th grade through 12th grade
- ☐ High school graduate
- ☐ Some college
- ☐ College graduate
- ☐ Graduate degree

7. Have you ever been in a focus group before?

- ☐ Yes
- ☐ No

First Card Sort
Where you get information

(Most information)

1. _____

2. _____

3. _____

4. _____

5. _____

6. _____

7. _____

8. _____

(Least information)

Second Card Sort (How much trust)

(Most trust)

1. _____

2. _____

3. _____

4. _____

5. _____

6. _____

7. _____

8. _____

(Least trust)